

**NGO Joint Parallel Report on the  
Russian Federation**

---

*Submission to the United Nations  
Universal Periodic Review  
for consideration in the formulation of the List of Issues  
during the 30th Session of the UPR Working Group  
Human Rights Council  
May 2018*

Submitted by online portal and electronic mail on October 5, 2017 on behalf of:

<i>International Human Rights Clinic Loyola Law School, Los Angeles 919 Albany Street 90015, Los Angeles, CA, USA Contact: Prof. Cesare Romano <a href="mailto:cesare.romano@lls.edu">cesare.romano@lls.edu</a> Prof. Mary Hansel <a href="mailto:mhansel@lls.edu">mhansel@lls.edu</a></i>	<i>SROO Sutyajnik Turgenev Str., 11-1 Yekaterinburg 620075, Russian Federation Contact: Dr. Anton Burkov <a href="mailto:ab636@cantab.net">ab636@cantab.net</a></i>
--	---

## I. INTRODUCTION

1. This report is submitted by the International Human Rights Clinic at Loyola Law School, Los Angeles located in Los Angeles, California, U.S.A., and Sutyajnik, a non-governmental organization based in Yekaterinburg, Russian Federation (“Russia”).
2. The International Human Rights Clinic at Loyola Law School, Los Angeles is committed to achieving the full exercise of human rights by all persons, and seeks to maximize the use of international and regional political, judicial, and quasi-judicial bodies through litigation, advocacy, and capacity-building.
3. Founded in Yekaterinburg, Russia in 1994, Sutyajnik is a human rights resource center that helps citizens and organizations realize rights guaranteed in the Russian Constitution and international treaties by litigating public interest cases, educating in human rights, and informing the public about the mechanisms for human rights protection. One of Sutyajnik’s principal goals is to defend human rights by working to bring domestic legislation and practice into conformity with international and constitutional standards.
4. This report examines a selection of human rights issues posed by the current legal scheme of the Russian Federation (“Russia”) governing bodily organ donations for purposes of transplantation. The current and longstanding legal scheme for organ donations is one that presumes each individual has consented to having his/her organs removed upon death, unless and until the individual or that individual’s family or legal representative has objected.
5. This “presumed consent” system lacks the clarity and safeguards necessary to ensure that individuals and their families know how to opt out of organ removal and what will happen if they do not opt out. As a result, citizens do not have a meaningful opportunity to provide or withdraw their consent.
6. First, Russia has not provided a mechanism for its citizens and their family members to express and document their donative intent. There is no easy prescribed opt-out procedure, as required by international standards.
7. Moreover, with respect to situations where an individual is at the hospital with fatal injuries, there is a lack of clarity regarding whether (a) the hospital must inform the individual’s family members of any plan to harvest organs and proactively seek consent from the individual’s family or (b) the family members have the burden of guessing as to the individual’s condition and the hospital’s organ removal plans and then demanding to opt out of the presumption of consent. Currently, Russian doctors openly confirm that they do not generally inform relatives of planned organ removals nor seek consent. The state contends that under the legal scheme, they are not required to do so and the burden rests on the family. However, state officials have also admitted that they are confused about this issue and have started and halted prosecutions of doctors removing organs without consent because of their confusion.
8. Furthermore, as public surveys have shown, Russia has failed to adequately inform its citizenry of the presumed consent system and the fact that individuals must opt out to avoid organ removal. Even if more members of the public were aware of the legal scheme, they would likely be confused as to how to opt out given that there is no mechanism for doing so.

9. As a result of this system and its deficiencies, state hospitals are removing individuals' organs in secret and against the wishes of the deceased and their families. The legal scheme and its application violate *inter alia* the right to privacy and the right to information. The scheme is particularly harmful and exploitative to vulnerable groups.

## **II. FACTUAL BACKGROUND**

### **A. Presumed Consent for Organ Donation Laws**

10. It is beyond dispute that the demand for organs far exceeds the donated supply throughout the world. Given this mass shortage, proponents of presumed consent laws argue that such laws boost the numbers of organ donations and, in turn, the number of transplants.<sup>i</sup>
11. Detractors, however, assert that presumed consent systems “essentially give[] the state a right of eminent domain over the body parts of a potential donor.”<sup>ii</sup> Critics also point out that, paradoxically, “[n]ations that employ presumed consent have seen no clear-cut relationship between the laws and high donation rates.”<sup>iii</sup> Moreover, critics emphasize that presumed consent laws effectively discriminate against marginalized, uneducated groups with severe consequences; for these groups are the least likely to be aware of their right to opt out of the presumption.<sup>iv</sup>
12. To be sure, several other countries aside from Russia have presumed consent laws for organ donation (although the recent trend in Europe has been away from such laws and toward opt-in legislation).<sup>v</sup> However, none of the existing systems of presumed consent allows a situation in which consent is not sought at all.<sup>vi</sup> Only Russia has a system where no consent is sought during the lifetime of individuals and no consent is sought from relatives at the time of death.<sup>vii</sup> Therefore, as explained below, Russia's system is actually “imputed” instead of “presumed.”

### **B. Russia's Presumed Consent Legal Scheme**

#### *The Transplantation Act*

13. Russian Federal Law no. 4180-1, entitled “On Transplantation of Human Organs and/or Tissues” (“the Transplantation Act”), was enacted on December 22, 1992 and establishes a presumption of consent on behalf of an individual or that individual's family to the post-mortem removal of organs for the purpose of transplantation.<sup>viii</sup> Section 8 of this law provides:

“that the extraction of organs and/or tissues from a human body is not allowed where a medical institution has been made aware that the deceased during his or her lifetime, or his or her close relatives or legal representative, have opposed the extraction of that person's organs or body tissues after his or her death for the purposes of transplantation.”<sup>ix</sup>
14. By its own terms, the Transplantation Act also provides that organ transplantation “must be performed in compliance with Russian laws and international human rights standards, respecting the principles proclaimed by the international community.”<sup>x</sup>
15. Further, the Act makes clear that “the interests of a particular individual are to prevail over those of society and science.”<sup>xi</sup>

### *The Burial Act*

16. Section 5 of the 1996 Russian law entitled “On Burial and the Funeral Business” (“the Burial Act”) states that each individual can express his/her will with respect to the treatment of his/her body after death, including organ removal.<sup>xii</sup>
17. The Act also provides that if an individual does not express his/her will, the right to consent or refuse consent falls to a close relative or legal representative.<sup>xiii</sup>

### *Decision of the Constitutional Court of Russia*

18. On December 4, 2003, Russia’s Constitutional Court found that the policy of presumed consent as established in the Transplantation Act is compatible with the Russian Constitution.<sup>xiv</sup> The Constitutional Court reasoned that it is “inhumane to put the question of harvesting organs or tissues to a person’s relatives at practically the same time as they are notified of his death, or immediately before an operation or other type of medical treatment” and concluded that Section 8 “is not unclear or ambiguous per se and therefore cannot be held to contravene individuals’ constitutional rights.”<sup>xv</sup> On 10 February 2016 the Constitutional Court confirmed this position<sup>xvi</sup>.
19. At the same time, the Constitutional Court emphasized that more detailed regulation was still necessary in the form of legal acts and other instruments to allow an individual or his/her relatives to exercise their right to express their will regarding organ donation.<sup>xvii</sup>

### *Russia’s Admission of Conflicting and Confusing Organ Donation Laws and Resultant Failures to Prosecute the Removal of Organs Without Consent*

20. Russia has admitted that Section 8 of the Transplantation Act and Section 5 of the Burial Act are in conflict regarding the exact nature of the state’s obligations. Russia has further admitted that the conflict between these provisions has impaired the prosecution of medical professionals who remove individuals’ organs without consent.
21. For example, Russia responded to a 2002 questionnaire from the Secretary General of the Council of Europe regarding official investigations and prosecutions related to organ trafficking. In its response, Russia stated that despite the initiation of proceedings based on credible allegations that local doctors had removed organs without permission from the deceased or his/her family, authorities had not pursued these proceedings because of “contradictions in the existing legislation,” leading to the conclusion that organ removal without consent may not constitute a crime.<sup>xviii</sup>
22. Because of the apparent conflict between and confusion surrounding these two legal provisions, it does not appear that Russia has prosecuted anyone for this practice despite numerous reports of organ removal without consent.<sup>xix</sup>
23. Russian lawmakers have known about the confusion caused by these laws since at least April 2002, when the Prosecutor General’s Office (in response to allegations of non-consensual organ removal) proposed revisions to the legislation in a letter to the Russian legislature.<sup>xx</sup> Now, fifteen years later, the state has yet to provide clarification of this legal scheme.

### *The Health Protection Act*

24. On November 21, 2011, Russia enacted Federal Law no. 323-FZ entitled “On the Basic Principles of Public Health Protection in the Russian Federation” (“the Health Protection

Act”), which provides in section 47(6) that “every mentally competent adult person is allowed, either orally in the presence of witnesses or in writing (certified by a notary or the chief medical officer of a medical institution), to express his or her consent or to oppose organ removal from his or her body after death.”<sup>xxi</sup> Section 47(7) of the Act provides that where the deceased has expressed no donative intent, his/her spouse or close relatives can oppose transplantation.<sup>xxii</sup> Section 47(10) prohibits the removal of organs where a medical institution is aware that a deceased person, or a close relative or legal representative, has opposed the removal of organs for transplantation purposes.<sup>xxiii</sup>

25. While Russia should have enacted legislation clarifying the conflict between the Transplantation Act and the Burial Act, it effectively confirmed and exacerbated the confusion between the two.
26. In April 12, 2017, the Ministry of Health introduced a draft law that does not substantially change or clarify the presumed consent scheme enacted in the Transplantation Act.<sup>xxiv</sup>

#### *Lack of Mechanism and Opportunity to Opt Out of Presumed Consent*

27. To date, Russia has not set forth a mechanism for its citizens and their family members to express and document their donative intent. The state has not contested this fact in relevant litigation before the European Court of Human Rights.<sup>xxv</sup> Indeed, there is no centralized database or similar means for seeking or tracking donor consent or providing citizens with any documentation reflecting their consent (such as a driver’s license with indications of donor status).<sup>xxvi</sup> Thus, medical institutions are often unaware that individuals have expressed their donative intent.<sup>xxvii</sup>
28. Compounding this problem is Russia’s failure to adequately inform citizens about the presumed consent scheme and the act that their organs may be removed if they do not opt out. In fact, a series of public surveys has established that only a small percentage of the population is aware of the legal scheme for organ donation. One of these surveys, conducted in 2017, revealed that the majority of the population (62.3%) did not know anything about the fact that doctors may remove their organs without their consent.<sup>xxviii</sup> Another survey found that “[t]he analysis of the data showed that organ donation and organ transplantation are subjects which are quite complex and unfamiliar to respondents.”<sup>xxix</sup>
29. Meanwhile, doctors and hospital staff are not obliged to seek consent or let relatives or legal representatives know of their intent to harvest organs. On the contrary, Russian doctors openly confirm that they do not inform relatives of planned organ removals.<sup>xxx</sup> Without being informed of such intent, family members and legal representatives cannot know that they need to opt out or when and how to do so.<sup>xxxi</sup>
30. Nonetheless, Russia asserts that relatives have the burden of informing the hospital of any objections regarding organ removal — although they may not even know that their family member is dying or that a hospital intends to harvest his/her organs — rather than requiring hospitals to inform relatives of planned organ removals and seek consent.
31. Even worse, many doctors proactively alert transplantologists of potential donors under their care, while neglecting to inform relatives that they intend to harvest their family member’s organs. A 2013 case decided by the Kirovsky district court of Omsk revealed that a hospital concluded a formal agreement with the transplantology clinic that removed the organs of the applicant’s son.<sup>xxxii</sup> Under this agreement the hospital was obligated to inform the transplantology clinic about any “potential donor.”

32. In fact, the term “presumed consent” as defined in Section 8 of the Transplantation Act, and as understood in medical and legal practice, actually means “artificial” or “imputed” consent (“вменное согласие”) rather than “presumed consent.” This is because consent is presumed even when close relatives are present at a hospital and medical personnel can easily approach and inform them about planned organ removal and ask for consent.

**C. Pending European Court of Human Rights Cases Against Russia Challenging the Presumed Consent Legal Scheme**

33. Recent cases brought before the European Court of Human Rights illustrate some of the human rights abuses that stem from Russia’s legal scheme regarding organ donation.

34. One of these cases is *Sablina and Others v. Russia* No. 4460/16 lodged on 28 December 2015, currently pending before the Court. The established facts of this case are as follows:

35. On January 11, 2014, Alina Sablina, a 19-year old student, was hit by a car while crossing the street on zebra crossing. As a result, she was severely injured and fell into a coma from which she never awoke.<sup>xxxiii</sup> Alina’s close relatives were in constant contact with the doctors, and visited their daughter in the hospital twice a day every day after her admission.<sup>xxxiv</sup> On January 17th, the family was told they could no longer see her.<sup>xxxv</sup> That night, brain death was recorded.<sup>xxxvi</sup> The hospital did not inform her relatives of her death (they found out from a burial agent), and did not provide them with details about the circumstances and cause of her death.

36. Four hours after Alina’s death was recorded, her organs were removed. At no point before or during these four hours did anyone at the hospital ask Alina’s family about consent for organ removal.

37. Her family did not even find out about the organ removal until one month later when they reviewed a forensic report in connection with a criminal investigation of the driver that hit her. The forensic report stated that six of Alina’s organs had been removed.<sup>xxxvii</sup> Her family later found out that only two of these six organs were recorded in the act of organs removal document. Four of the six organs removed had been omitted from the act of organs removal document.<sup>xxxviii</sup>

38. Alina never expressed her consent to donate her organs.<sup>xxxix</sup> Alina’s family members were never informed that the hospital sought to harvest her organs.<sup>xl</sup> They were not asked about Alina’s donative intent.<sup>xli</sup> They were not asked for their consent.<sup>xlii</sup> Nonetheless, investigators told them that the organ removal was legal, because they failed to let doctors know that they objected to the procedure and the doctors had no legal obligation to seek their consent.<sup>xliii</sup>

39. Alina’s family brought civil claims against the hospital in lower, appellate and cassation courts.<sup>xliv</sup> Separately, the family challenged the Transplantation Act’s compatibility with the Russian Constitution and European Convention on Human Rights before the Constitutional Court.<sup>xlv</sup> After exhausting remedies, the family brought their claims to the European Court of Human Rights, where the action is currently pending.

40. A similar case pending before the European Court of Human Rights, *Galina Petrovna VALYUSHCHENKO against Russia* lodged on 22 June 2014, also involves the removal of an individual’s organs for transplantation without the consent of the individual or his

family.<sup>xlvi</sup> The Court’s questions to the parties for briefing reflect the human rights issues posed by the legal scheme, for example: “[W]as any system of informing the general public about that [organ donation] legislation, and/or regulation in that area, in place, in accordance with the Russian Constitutional Court’s decision [in] 2003?”, “Did the relevant Russian legislation as in force at the time provide sufficient protection against arbitrariness?” and “Was there any system in place of informing relatives of those deceased whose organs had been removed for the purpose of transplantation of that fact?”

41. In essence, Russia’s position in these cases is that authorities (including doctors in state-run clinics) have no obligation to inform relatives about planned organ removal or seek their consent. The state maintains that the legal scheme makes clear that doctors have no obligation to inform relatives about planned organ removals — which effectively means that relatives of the putative donor must guess that their relative qualifies as a donor and must approach doctors and state that they or the potential donor object to organ removal. If they fail to do so, according to the state, then consent is presumed and medical personnel have unfettered discretion to remove organs as they see fit and need not even let the family know about the removal after the fact.

#### IV. ANALYSIS

##### **A. Russia’s Presumed Consent Legal Scheme Violates the Right to Privacy.**

###### *The Right to Privacy Under Applicable International Human Rights Law*

42. The right to privacy has been enshrined as a fundamental right prohibiting state interference in personal and family life.<sup>xlvii</sup> The International Covenant on Civil and Political Rights (ICCPR), the Convention on the Rights of Persons with Disabilities (CRPD), the Convention on the Rights of the Child (CRC) and the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR) define this right as one against arbitrary or unlawful interference with an individual’s privacy, family, home, correspondence, honor or reputation.<sup>xlviii</sup>
43. International jurisprudence emphasizes that the right to privacy is especially critical with respect to an individual’s physical body and familial relationships.<sup>xlix</sup> For example, in *Toonen v. Australia*, the Human Rights Committee denounced a Tasmanian law effectively criminalizing homosexuality because it unreasonably intruded upon private sexual activities between consenting adults and was not proportionally limited to meet its purported aims.<sup>1</sup> The Committee emphasized that Australia failed to show any evidence linking the criminalization of homosexuality to decreased incidence of HIV/AIDS.<sup>li</sup>
44. Meanwhile, the European Court of Human Rights (ECtHR) has found that non-consensual medical examination or treatment may also amount to a violation of the right to privacy. In *Glass v. the United Kingdom*, the ECtHR held a doctor’s decision to administer diamorphine to a young boy, despite his mother’s refusal, violated both the mother’s and child’s rights to privacy.<sup>lii</sup> It explained that neither the urgency of the situation nor the doctor’s medical expertise were sufficient to override the mother’s objection.<sup>liii</sup>
45. States are not only required to refrain from intrusive conduct; they must take positive actions to protect and fulfill their obligations with respect to the right to privacy. A state’s obligations involve the adoption of measures, including the implementation of procedural safeguards, designed to secure respect for private and family life.<sup>liv</sup>

###### *The Right to Privacy in the Context of Organ Donation*

46. Numerous international organizations and UN bodies have recognized the unique dangers of transnational organ trafficking on the right to privacy.<sup>lv</sup> As such, while the overwhelming global need for organs supports the need for organ transplantation, organ removals should be regulated and not financially benefit the donor or donor's family.<sup>lvi</sup>
47. International law distinguishes between opt-in and presumed consent organ removal laws. In the Convention on Human Rights and Biomedicine, which first emphasized the primacy of an individual's human rights over societal interests for organ transplantation, the Council of Europe deemed consent critical to the validity of a State's organ removal and/or transplantation law.<sup>lvii</sup>
48. Subsequently, the World Health Organization (WHO) stated that opt-out laws should ensure that individuals have not refused consent by establishing clear and easy opt-out procedures.<sup>lviii</sup> As such, an individual's autonomy in choosing to consent or not consent must be paramount in determining whether his/her organs may be harvested.<sup>lix</sup>
49. The European Group on Ethics in Science and New Technologies has stated that "[c]onsent of a donor for retrieval of tissues after death may take different forms depending on the national systems ('explicit' or 'presumed' consent). However, no retrieval of tissues may take place, with the exception of judicial proceedings, if the party concerned formally objected while alive. Furthermore, if there has been no expression of will and the applicable system is that of 'presumed' consent, doctors must ensure as far as possible that relatives or next of kin have the opportunity to express the deceased person's wishes, and must take these into account."<sup>lx</sup>
50. Two key European Court of Human Rights cases, *Petrova v. Latvia* and *Elberte v. Latvia*, are particularly instructive with respect to the right to privacy issues posed by Russia's legal scheme.<sup>lxi</sup> At the time each of these cases was decided, Latvia had an organ donation law very similar to Russia's current legal scheme. However, unlike the Russian scheme lacking an opt-out mechanism, the operative Latvian law provided that a person "must apply to the Office of Citizenship and Migration Affairs, in accordance with a procedure prescribed by regulations issued by the Cabinet of Ministers, to exercise the right to consent or object to the use of his or her body after death."<sup>lxii</sup> Notwithstanding the provision of this mechanism, the Court still found the Latvian law and its application to be insufficiently clear and thus in violation of the right to privacy. Since these cases were decided, Latvia has amended its laws to avoid the right to privacy violations found by the Court.
51. In *Petrova v. Latvia*, the Court found a mother's right to privacy had been violated when her son's kidneys and spleen were removed after he was categorized "fatal" without her knowledge or consent.<sup>lxiii</sup> She was not informed when her son's condition started to deteriorate.<sup>lxiv</sup> And she was not asked whether her son had consented to being an organ donor, nor whether she would consent to organ donation in the absence of any wishes expressed by her son.<sup>lxv</sup> Nine months later, she obtained a copy of the forensic report from which she learned that certain organs had been removed from her son's body for transplantation purposes.<sup>lxvi</sup>
52. The Court reasoned that to justify state interference, the state must show *inter alia* that the interference was "in accordance with the law," which "means that the domestic law must be formulated with sufficient precision and must afford adequate legal protection against arbitrariness."<sup>lxvii</sup> Specifically, the law "must indicate with sufficient clarity the scope of discretion conferred on the competent authorities and the manner of its exercise."<sup>lxviii</sup> The Court underscored that "the principle of legality requires States not

only to respect and apply, in a foreseeable and consistent manner, the laws they have enacted, but also, as a necessary part, to ensure the legal and practical conditions for their implementation.”<sup>lxi</sup>

53. The Court noted a disagreement among Latvian authorities as to the obligations of medical personnel — similar to the confusion that exists among Russian authorities, described above — and found that such disagreement demonstrated a “lack of reasonable clarity.” Also, the Court found that “it remains unclear how the ‘presumed consent system’, as established under the Latvian law, operates in practice in the circumstances in which the applicant found herself, whereby she had certain rights as the closest relative but was not informed – let alone provided with any explanation – as to how and when these rights might have to be exercised.”<sup>lxx</sup> The Court concluded that “[w]hile Latvian law set out the legal framework allowing the closest relatives to express their wishes in relation to organ removal for transplantation purposes, it did not define with sufficient clarity the scope of the corresponding obligation or the discretion conferred on medical practitioners or other authorities in this respect.”<sup>lxxi</sup>
54. The Court held that the Latvian law was not “formulated with sufficient precision or afforded adequate legal protection against arbitrariness” and therefore violated the right to privacy.<sup>lxxii</sup>
55. Similarly, in *Elberte v. Latvia*, the ECtHR held that Latvia’s law violated a woman’s right to privacy when her husband’s tissue had been removed during a forensic autopsy without her knowledge or consent.<sup>lxxiii</sup>
56. The Court engaged in the same analysis used in *Petrova* and likewise decided that the law violated the right to privacy. The Court found that “although Latvian law set out the legal framework allowing the closest relatives to express consent or refusal in relation to tissue removal, it did not clearly define the scope of the corresponding obligation or the margin of discretion conferred on experts or other authorities in this respect.”<sup>lxxiv</sup>
57. The Court made a point of emphasizing that “the relevant European and international documents on this matter accord particular importance to the principle that the relatives’ views must be established by means of reasonable enquiries . . . If the wishes of the deceased are not sufficiently clearly established, relatives should be contacted to obtain testimony prior to tissue removal.”<sup>lxxv</sup>

*The Russian Organ Donation Legal Scheme’s Lack of Sufficient Precision and Clarity in Violation of the Right to Privacy*

58. Based on the authorities discussed above, Russia’s organ donation legal scheme does not comply with the human rights requirements for presumed consent laws. Accordingly, the legal scheme violates the right to privacy.
59. International standards and case law make clear that presumed consent programs must include clear and easy opt-out procedures. Russia’s scheme does not have such procedures, despite calls for their implementation. By contrast, the former Latvian opt-out law, denounced in the *Petrova* and *Elberte* cases, did include a formal opt-out mechanism — yet was still deemed insufficiently clear and precise. The legal threshold for opt-out mechanisms is stringent and Russia’s scheme falls far short.
60. The relevant standards and cases also establish that medical personnel must proactively seek to ascertain donative intent and provide family with a meaningful opportunity to

give or refuse consent. The application of Russia's laws has shown that doctors do not feel compelled to do so and, in fact, do not do so.

61. The lack of clarity and precision is underscored by the fact that even state officials have admitted their confusion over the obligations of medical professionals (specifically, with respect to the conflict between the Transplantation Act and the Burial Act). Indeed, Russia has stated that this confusion is the reason authorities have not prosecuted any doctors for the unlawful removal of organs.
62. Finally, there does not seem to be evidence that the legal scheme has actually increased the incidence of organ transplantation. Rather, in spite of its liberal approach in favor of donation, the state has had three to four times fewer incidences of organ transplantation than states with stricter laws.<sup>lxxvi</sup> This fact undermines any state argument that its intrusiveness is somehow justified by a legitimate aim.

**B. Russia's Presumed Consent Legal Scheme Also Violates the Right to Information and Promotes Discrimination.**

*The Right to Information Under International Human Rights Law*

63. Russia has ratified multiple treaties that set forth the right to information, and is therefore bound to take measures to uphold and fulfill this right.
64. For example, Article 19 of the International Covenant on Civil and Political Rights, reiterates the language used in the Universal Declaration of Human Rights, highlighting the importance of the ability to exchange information.<sup>lxxvii</sup> Also, Article 10 of the European Convention for the Protection of Human Rights and Fundamental Freedoms guarantees that people can "receive and impart information and ideas without interference by public authority."<sup>lxxviii</sup>
65. The right to information requires states to do more than merely refrain from impeding access to information. States must "ensure easy, prompt, effective and practical access" to information.<sup>lxxix</sup> Indeed, "[t]o give effect to the right of access to information, States parties should proactively put in the public domain Government information of public interest."<sup>lxxx</sup> And "States parties should also enact the necessary procedures, whereby one may gain access to information" and "widely publish and disseminate documents of significant public interest" with an eye toward maximum disclosure.<sup>lxxxi</sup>
66. Russia not only has an obligation to inform people about the presumed consent law, it must also provide the information necessary for them to provide or refuse to provide consent.
67. As WHO states, "[p]rogrammes are more able to rely on the deceased's explicit or presumed consent, without seeking further permission from family members, when the public's understanding and acceptance of the process of donating cells, tissues and organs is deep-seated and unambiguous."<sup>lxxxii</sup> The onus is on the state to ensure that all citizens are fully aware and informed.
68. WHO also states that the information regarding the presumed consent system must be communicated in a full, objective and locally relevant manner, which respects the intimacy and complexity of making such a decision.<sup>lxxxiii</sup>
69. Indeed, "a massive public education campaign is needed to ensure that all citizens are fully aware of their right to opt out of the system. This aids in ensuring that a person who

does not opt out of the system has made a voluntary, informed decision to do so and is not simply ignorant of the right to object to organ donation.”<sup>lxxxiv</sup>

*Russia’s Failure to Meet its Obligations Pursuant to the Right to Information Resulting in Clandestine Organ Removals and Discriminatory Effects for Vulnerable Groups*

70. Unfortunately, Russia has not met its obligations to ensure citizen awareness pursuant to the right to information. As noted above, a series of public surveys has established that only a small percentage of the population is aware of the legal scheme. A 2017 survey demonstrated that 62.3% of the population knew nothing about the fact that doctors may remove their organs without their consent.<sup>lxxxv</sup> Even if more members of the public were aware of the legal scheme, they would likely be confused as to how to opt out given that there is no mechanism for doing so.
71. The lack of awareness and confusion regarding the legal scheme results in disjointed applications of the law and gives unfettered discretion to state officers, agents and medical personnel. The Chairman of Russia’s National Patient Safety Agency, Alexei Strachenko, has highlighted this issue, pointing out that every transplantation facility follows its own policies.<sup>lxxxvi</sup> Strachenko has explained that such disparate protocols breed corruption, because without a coherent and transparent system the Russian government could continue to intrude upon individuals’ human rights without detection or recourse.<sup>lxxxvii</sup>
72. Moreover, the issues surrounding the application of the presumed consent scheme have profound effects on everyone in Russia, but can have a particularly harsh impact on vulnerable groups such as women, children, people who are economically depressed, people with disabilities and people who are not literate.
73. Such marginalized groups are likely unable to obtain access to the information needed to opt out of the presumed consent scheme.<sup>lxxxviii</sup> “Consequently, the law will have a disparate impact on the disenfranchised who will, in essence, be supplying transplant organs for the wealthy.”<sup>lxxxix</sup>

\* \* \*

74. In conclusion, Russia’s legal scheme, as currently written and implemented, violates the right to privacy and the right to information. The scheme also poses risks for discrimination against vulnerable groups. To be sure, there are additional rights implicated by the scheme; however, spatial constraints prevent their discussion in this report.

**V. RECOMMENDATIONS**

75. In light of these violations and considering the information set forth above, the submitting parties respectfully request that the Human Rights Council add the issue of Russia’s organ donation legal scheme to the list of issues and adopt the following recommendations:
  - (1) Russia should amend its current legislation to resolve any conflicts and ensure the requisite precision and clarity. Such clarity is especially needed to establish that medical personnel have the burden to proactively inform the relatives of putative donors that they intend to harvest organs and proactively seek and confirm that there is consent or a lack of consent for organ removal.

- (2) Russia should adopt an easily accessible, formal mechanism through which the individuals' donative intent can be registered.
- (3) Russia should consider changing its organ donation system to an opt-in program.
- (4) Once legally sufficient legislation has been implemented, Russia should publicize the legal scheme and mechanism with special attention to marginalized and poorly educated people.
- (5) Once legally sufficient legislation has been implemented, Russia should vigorously pursue criminal investigations and prosecutions of unlawful organ removals.
- (6) Once legally sufficient legislation has been implemented, Russia should install oversight mechanisms that assess the effectiveness of these changes and improve overall accountability and transparency.

<sup>i</sup> See, e.g., Everton Bailey, *Should the State Have Rights to Your Organs? Dissecting Brazil's Mandatory Organ Donation Law*, 30 U. MIAMI INTER-AM. L. REV. 707 (1999).

<sup>ii</sup> Traci J. Hoffman, *Organ Donor Laws in the U.S. and the U.K.: The Need for Reform and the Promise of Xenotransplantation*, 10 IND. INT'L & COMP. L. REV. 339, 350 (2000)

<sup>iii</sup> *Ibid.*; See also ORGANISATION FOR ECONOMIC CO-OPERATION AND DEVELOPMENT, XENOTRANSPLANTATION: INTERNATIONAL POLICY ISSUES, (1999).

<sup>iv</sup> Bailey, *supra* note i, at 720-21.

<sup>v</sup> *Ibid.*

<sup>vi</sup> Reply Brief for Petitioner, Sablina and Others v. Russia, Eur. Ct. H.R., No. 44460/16, ¶ 26.1 (2017).

<sup>vii</sup> *Ibid.*

<sup>viii</sup> Федеральный Закон от 22.12.1992 № 4180-1 “О трансплантации органов и (или) тканей человека” (hereinafter, “Transplantation Act”).

<sup>ix</sup> Application to the Court, Sablina and Others v. Russia, Eur. Ct. H.R., No. 44460/16, Statement of Facts and Questions, ¶¶ 5-6, Sept. 21, 2016 (hereinafter, “Sablina v. Russia Statement”); Transplantation Act, *supra* note viii, art. 8. The full English translation of Article 8 is as follows: “The removal of organs and (or) tissues from a corpse is not allowed if the health care institution at the time of removal was informed that this person during his life or his close relatives or the legal representative stated their disagreement to removal of his organs and (or) tissues after death for transplantation to a recipient.”

<sup>x</sup> Sablina v. Russia Statement, *supra* note ix, at ¶¶ 5-6; Transplantation Act, *supra* note viii, at Preamble.

<sup>xi</sup> Sablina v. Russia Statement, *supra* note viii, at ¶ 5.

<sup>xii</sup> Application to the Court, Sablina and Others v. Russia, *supra* note ix, at “Supplement” ¶

2.

<sup>xiii</sup> *Ibid.*

<sup>xiv</sup> L.V. Zhytynsky v. Saratov, SOBRANIE ZAKONODATEL'STVA ROSSIISKOI FEDERASTII [SZ RF] [Russian Federation Collection of Legislation] Dec. 4, 2003, No. 459-O.

<sup>xv</sup> *Ibid.*

<sup>xvi</sup> See the Constitutional Court's decision No. 224-O dated 10 February 2016. The case was initiated by the application by Sablina and others, which became a ground for the case *Sablina and Others v. Russia*. The document was not published.

<sup>xvii</sup> *Ibid.*

- xviii Council of Europe, Steering Committee On Bioethics & European Health Committee, *Replies to the questionnaire for member states on organ trafficking*, CDBI/INF (2003) 11 rev. 2 (June 2, 2004); *see* Application to the Court, Sablina and Others v. Russia, *supra* note viii, at “Supplement” ¶ 4.
- xix *See* Application to the Court, Sablina and Others v. Russia, *supra* note ix, at “Supplement” ¶ 5.
- xx *See* Application to the Court, Sablina and Others v. Russia, *supra* note ix, at “Supplement” ¶ 6.
- xxi Sablina v. Russia Statement, *supra* note viii, at ¶ 6; Федеральный Закон от 21.11.2011 № 323-ФЗ “Об основах охраны здоровья граждан в Российской Федерации.”
- xxii Федеральный Закон от 21.11.2011 № 323-ФЗ “Об основах охраны здоровья граждан в Российской Федерации,” *supra* note xxii.
- xxiii *Ibid.*
- xxiv Reply Brief for Petitioner, Sablina and Others v. Russia, *supra* note vi, at ¶ 29.1. *See also* Gabbasova Lialia Adygamovna, Asst. to the Russian Minister of Health, Address at the Implementation of International and Constitutional Guarantees of Human Rights in Russian Law and Practice: Questions of Bioethics in Medical Practice in Russia (Surrogacy, Transplantation) (Apr. 12, 2017) (video available at <http://sutyajnik.ru/news/2017/04/2775.html>).
- xxv Reply Brief for Petitioner, Sablina and Others v. Russia, *supra* note vi, at ¶ 15.
- xxvi *See* Elena Anatolyevna Kirillova and Varvara Vladimirovna Bogdan, *Actual Problems of Post-Mortem Organ Donation by Bequest in the Law of Succession in Russia: A Comparative Legal Analysis*, 15:8 MIDDLE E. J. OF SCI. RES. (2013).
- xxvii *Ibid.*
- xxviii *Report on the results of sociological survey “Transplantation (removal) of organs from deceased patients without their consent in their lifetime, or the consent of their relatives,”* SUTYAJNIK, Yekaterinburg, (2017), available at <http://sutyajnik.ru/documents/5030.pdf>.
- xxix Olga Karaeva, *Donorstvo organov: problem i perspektivy razvitiya v Rossii* (Moskva: Levada-Tsenter, 2013), available at [http://www.levada.ru/old/sites/default/files/otchet\\_donorstvo\\_organov\\_v\\_rossii\\_1\\_evada-centr.pdf](http://www.levada.ru/old/sites/default/files/otchet_donorstvo_organov_v_rossii_1_evada-centr.pdf).
- xxx *Id.* at ¶ 17.
- xxxi *Id.* at ¶¶ 10-11.
- xxxii Case No 2-5181/2013, Kirovsky dist. ct. Omsk, Judgment, Oct. 23, 2013, at 6.
- xxxiii Sablina v. Russia Statement, *supra* note viii, at ¶ 1.
- xxxiv *Ibid.*
- xxxv *Id.* at ¶ 2. *See also* Reply Brief for Petitioner, Sablina and Others v. Russia, *supra* note vi, at ¶ 2.3.
- xxxvi Sablina v. Russia Statement, *supra* note viii, at ¶ 2.
- xxxvii *Ibid.*
- xxxviii Reply Brief for Petitioner, Sablina and Others v. Russia, *supra* note vi, at ¶¶ 2.5-2.6.
- xxxix *Id.* at ¶ 7.
- xl *Ibid.*
- xli *Ibid.*
- xlII *Ibid.*
- xlIII Sablina v. Russia Statement, *supra* note viii, at ¶ 2.
- xliv *Id.* at ¶¶ 2-5.
- xlv *Ibid.*
- xlvi Subject Matter of the Case and Questions, Valyushchenko v. Russia, Eur. Ct. H.R., No. 51283/14, at ¶ 1 (Jan. 10, 2017).
- xlvii *See* Universal Declaration of Human Rights, G.A. Res. 217 (III) A, U.N. Doc. A/RES/217(III), art. 12 (Dec. 10, 1948).
- xlviii *See* International Covenant on Civil and Political Rights, Mar. 23, 1976, 999 U.N.T.S. 171, art. 17 (hereinafter “ICCPR”); Convention on the Rights of Persons with Disabilities, Mar. 30, 2007, G.A. Res. 61/106, U.N. Doc. A/RES/61/106, 2515 U.N.T.S. 44910, art. 22(1)

---

(hereinafter “CRPD”); Convention on the Rights of the Child, Nov. 20, 1989, G.A. Res. 44/25, U.N. Doc. A/RES/44/25, 1577 U.N.T.S. 27531, art. 16 (hereinafter “CRC”); European Convention on the Protection of Human Rights and Fundamental Freedoms, Apr. 11, 1950, 213 U.N.T.S. 2889, art. 8 (hereinafter “ECHR”).

<sup>lix</sup> See United Nations Human Rights Committee, *Boodoo v. Trinidad and Tobago*, Communication No. 721/1996, U.N. Doc. CCPR/C/74/D/721 (1997); United Nations Human Rights Committee, *Toonen v. Australia*, Communication No. 488/1992, U.N. Doc. CCPR/C/50/D/488/1992 (1994); *Glass v. the United Kingdom*, Eur. Ct. H.R., No. 61827/00 (2004); *Worwa v. Poland*, Eur. Ct. H.R., No. 26624/95, 43 EHRR 35 (2003); *YF v. Turkey*, Eur. Ct. H.R., No. 24209/94 (2003).

<sup>l</sup> *Toonen v. Australia*, *supra* note *xlvi*, at ¶ 8.5.

<sup>li</sup> *Ibid.*

<sup>lii</sup> *Glass v. the United Kingdom*, *supra* note *xlvi*, at ¶¶ 70–72.

<sup>liii</sup> *Ibid.*

<sup>liv</sup> See, e.g., *X and Y v. the Netherlands*, 23 Eur. Ct. H.R. (ser. A.) ¶ 91 (1985) and *Ciubotaru v. Moldova*, Eur. Ct. H.R., No. 27138/04, § 51 (2010).

<sup>lv</sup> See U.N.GIFT Steering Committee, Joint Statement by the member organizations of the U.N.GIFT Steering Committee, January 2015 (Dec. 31, 2014), *available at* <http://www.ungift.org/knowledgehub/en/stories/March2015/joint-statement.html>; U.N. Office of the High Commissioner of Human Rights, Fact Sheet No. 36: Human Rights and Human Trafficking (2014), *available at* [http://www.ohchr.org/Documents/Publications/FS36\\_en.pdf](http://www.ohchr.org/Documents/Publications/FS36_en.pdf); U.N. Office on Drugs and Crime, Assessment Toolkit: Trafficking in Persons for the Purpose of Organ Removal (2015), *available at* [https://www.unodc.org/documents/human-trafficking/2015/UNODC\\_Assessment\\_Toolkit\\_TIP\\_for\\_the\\_Purpose\\_of\\_Organ\\_Removal.pdf](https://www.unodc.org/documents/human-trafficking/2015/UNODC_Assessment_Toolkit_TIP_for_the_Purpose_of_Organ_Removal.pdf). See also Yosuke Shimazono, The State of the International Organ Trade: A provisional picture based on integration of available information, WHO BULLETIN (Dec. 2007), *available at* <http://www.who.int/bulletin/volumes/85/12/06-039370.pdf?ua=1>.

<sup>lvi</sup> Erica Teagarden, *Human Trafficking: Legal Issues in Presumed Consent Laws*, 30 N.C. J. INT’L L. & COM. REG. 685, 686 (2005).

<sup>lvii</sup> Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Biomedicine: Convention on Human Rights and Biomedicine, arts. 2, 19, E.T.S. no. 164 (Apr. 4, 1997) (hereinafter, “Oviedo Convention”). See also World Health Organization, Guiding Principles on Human Cell, Tissue and Organ Transplantation, Commentary on Guiding Principle 1 (May 21, 2010).

<sup>lviii</sup> World Health Organization, *supra* note *lix*, Commentary on Guiding Principle 1.

<sup>lix</sup> *Ibid.* See also Oviedo Convention, *supra* note *lix*, at Art. 9 (where decedents’ “previously expressed wishes” for or against organ removal/donation may be helpful in determining whether she or he has consented).

<sup>lx</sup> World Health Organization, *supra* note *lix*, Guiding Principle 11. See also Oviedo Convention, *supra* note *lix*, at Art. 2.3.2.

<sup>lxi</sup> *Petrova v. Latvia*, Eur. Ct. H.R., No. 4605/05 (2014); *Elberte v. Latvia*, Eur. Ct. H.R., No. 61243/08 (2015).

<sup>lxii</sup> *Petrova v. Latvia*, *supra* note *lxiii*, at ¶ 35.

<sup>lxiii</sup> *Id.* at ¶¶ 8-9, 97.

<sup>lxiv</sup> *Id.* at ¶ 10.

<sup>lxv</sup> *Ibid.*

<sup>lxvi</sup> *Id.* at ¶ 12.

<sup>lxvii</sup> *Id.* at ¶ 85, citing *A, B and C v. Ireland*, Eur. Ct. H.R., No. 25579/05, ¶¶ 218-41 (2010).

<sup>lxviii</sup> *Petrova v. Latvia*, *supra* note *lxiii*, at ¶ 86.

<sup>lxix</sup> *Id.* at ¶ 95, citing *Broniowski v. Poland*, Eur. Ct. H.R., No. 31443/96, ¶¶ 147 and 184 (2004).

<sup>lxx</sup> *Petrova v. Latvia*, *supra* note *lxiii*, at ¶ 95.

<sup>lxxi</sup> *Id.* at ¶ 94.

<sup>lxxii</sup> *Id.* at ¶¶ 95-96.

- 
- lxxiii *Elberte, supra note lxii*, at ¶¶ 12, 27, 107.
- lxxiv *Id.* at ¶ 113.
- lxxv *Ibid.*
- lxxvi *See Sociologists Develop Myths Around the Reasons for Insufficient Quantity of Donors*, SUTJAYNIK PRESS, (Mar. 23, 2016) available at <http://sutyajnik.ru/news/2016/03/2624.html>. (Available only in Russian).
- lxxvii ICCPR, *supra note xlv*, at Art. 19. Article 19 states: “Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.”
- lxxviii Convention for the Protection of Human Rights and Fundamental Freedoms, *supra note xlv*, at Art. 10(1).
- lxxix CCPR/C/GC/34 from Human Rights Committee 102nd Session 11-29 July 2011, para. 19.
- lxxx *Id.*, para 19.
- lxxxi U. N.Id.; United Nations General Assembly, Report of the Special Rapporteur on the promotion and protection of the right to freedom of expression, A/68/362, (Sept. 4, 2013). *See also* Article 19 Global Campaign for Free Expression, *The Public’s Right to Know: Principles on Freedom of Information Legislation* (London, 1999).
- lxxxii World Health Organization, *supra note lix*, Commentary on Guiding Principle 1.
- lxxxiii *Id.* at Guiding Principle 11.
- lxxxiv Bailey, *supra note i*, at 725.
- lxxxv *Report on the results of sociological survey “Transplantation (removal) of organs from deceased patients without their consent in their lifetime, or the consent of their relatives,”* SUTYAJNIK, Yekaterinburg, (2017), available at <http://sutyajnik.ru/documents/5030.pdf>.
- lxxxvi *In Russia, doctors can harvest organs without consent*, TIMES PICAYUNE (Apr. 15, 2016), available at [http://www.nola.com/politics/index.ssf/2016/04/russia\\_harvest\\_organ\\_consent.html](http://www.nola.com/politics/index.ssf/2016/04/russia_harvest_organ_consent.html).
- lxxxvii *Ibid.*
- lxxxviii *See* Bailey, *supra note i*, at 723–24.
- lxxxix *Ibid.*