Planned Parenthood Federation of America, Inc.

April 18, 2022

VIA ELECTRONIC TRANSMISSION

The Honorable Xavier Becerra, Secretary
U.S. Department of Health & Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Re: Information Collection Request on Consent for Sterilization Form (0937-0166)

Dear Secretary Becerra:

Planned Parenthood Federation of America (Planned Parenthood) submits these comments in response to the Agency Information Collection Request regarding the Consent for Sterilization Form (consent form) (OMB No. 0937-0166), released by the Department of Health and Human Services (HHS) and published in the federal register on February 15, 2022. As a trusted provider of sexual and reproductive health care, Planned Parenthood takes every opportunity to weigh in on policy proposals that impact the communities we serve across the country. We urge HHS to improve the consent form to ensure that decisions that patients make about their bodies are informed. We also support lifting the consent form's waiting period which creates unequal access to sterilization services based on a patient's insurance type.

Planned Parenthood is the nation's leading sexual and reproductive health care provider and advocate and a trusted, nonprofit source of primary and preventive care for people of all genders in communities across the United States. Planned Parenthood's health centers provide affordable birth control, lifesaving cancer screenings, testing and treatment for sexually transmitted infections, and other essential care to 2.4 million patients annually. Planned Parenthood health centers also provide abortion services and ensure that all people have accurate information about all of their reproductive health care options. One in five women in the U.S. has visited a Planned Parenthood health center. The majority (75%) of Planned Parenthood patients have incomes at or below 150 percent of the federal poverty level.

As a provider of contraceptive care, Planned Parenthood knows how important it is that patients have access to the contraception that they desire—including sterilization. Sterilization is the most commonly used contraceptive method among women aged 15–49; nearly one in five

women in this age group use sterilization as their contraceptive method.[1] At the same time, the patients we serve come from communities that have historically faced sterilization abuse—abuse that was driven by the eugenics movement that Planned Parenthood's own founder aligned with. Because of this history and the patients that we serve, Planned Parenthood is committed to improving the sterilization consent form so patients considering sterilization have the information they need, presented in an understandable way, to make a decision about their own bodies. We also support lifting the consent form's waiting period so that all patients, regardless of insurance type or income, have equal access to wanted contraception.

I. The necessity and utility of the proposed information collection.

The consent form plays the vital role of ensuring that only patients who understand and desire sterilization receive the service. While informed consent is critical for all types of care, it is especially important for sterilization because of this country's shameful history of sterilization abuse. This abuse includes people who were sterilized without their knowledge or consent when undergoing medical procedures or childbirth, as well as people who were coerced or deceived into giving consent for sterilization.

Sterilization was used as a weapon of oppression throughout the 20th century to maintain race, class, ability, and gender hierarchies and has disproportionately impacted people with disabilities, Mexican-origin, Black, Puerto Rican, and Indigenous women, immigrants, and people with low incomes. In the early 1900s, states began passing eugenics laws legalizing the forced sterilization of people "unfit to reproduce."[2] States interpreted these laws to target the aforementioned groups and women who had sex and became pregnant outside of marriage. Thirty-two states passed such sterilization laws in the first half of the 20th century, resulting in the forced sterilization of a staggering 60,000 people in state-run institutions and hospitals.[3]

These state sterilization programs initially targeted people with developmental and intellectual disabilities, people who violated sexuality norms, and people who had committed crimes.[4] Over time, people of color and women were increasingly targeted by eugenics practices.[5] From

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[1] Kimberly Daniels and Joyce C. Abma, "Current Contraceptive Status Among Women Aged 15–49: United States, 2017–2019," *National Center for Health Statistics Data Brief*, no. 388 (October 2020), https://www.cdc.gov/nchs/data/databriefs/db388-H.pdf.

[2] Lisa H. Harris and Taida Wolfe, "Stratified Reproduction, Family Planning Care and the Double Edge of History," *Current Opinion in Obstetrics & Gynecology* 26, no. 6 (December 2014): 539–44, https://doi.org/10.1097/GCO.0000000000000121.

[3] Alexandra Minna Stern, "Sterilized in the Name of Public Health - Race, Immigration, and Reproductive Control in Modern California," *American Journal of Public Health* 95, no. 7 (2005): 1128–38, https://doi.org/10.2105/AJPH.2004.041608.

[4] Stern, "Sterilized in the Name of Public Health."

[5] Alexandra Stern, "Forced Sterilization Policies in the US Targeted Minorities and Those with Disabilities – and Lasted into the 21st Century," University of Michigan Institute for Healthcare Policy & Innovation, September 23, 2020, https://ihpi.umich.edu/news/forced-sterilization-policies-us-targeted-minorities-and-those-disabilities-and-lasted-21st.

1950–1966, Black women in North Carolina were sterilized at more than three times the rate of white women and more than 12 times the rate of white men.[6] In Puerto Rico, a U.S.-instituted population control program, combined with colonialist economic reforms, resulted in over 34% of mothers aged 20–49 being sterilized by 1965.[7,8]

Sterilization abuse increased dramatically in 1970 with the passage of the Family Planning Services and Population Research Act, which subsidized sterilizations for patients who received care through Medicaid and the Indian Health Service (IHS).[9] In the 1970s, the IHS sterilized at least one in four Indigenous women between the ages of 15–44.[10] Some women were threatened that they would lose their children or their welfare benefits if they did not agree to sterilization; others gave "consent" during childbirth or while sedated or were not given consent forms they could understand.[11]

In response to this mass abuse, federal regulations introduced in 1974 mandated the use of the consent form and a 72 hour waiting period. After an extension of the waiting period to 30 days in 1978, neither the regulations nor the consent form have since changed.[12]

Sterilization abuse continues to this day. To name just a few examples: from 2005–2011, the state of California sterilized 39 female inmates without obtaining sufficient consent.[13] In 2017 and 2018, judges in Tennessee and Oklahoma offered reduced jail time to people with substance use disorders if they received sterilization or long-acting reversible birth control.[14,15] In 2020, a whistleblower report revealed that immigrants detained at the for-profit Irwin County ICE detention center in Georgia were subjected to forced hysterectomies and unnecessary medical

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[6] Stern, "Forced Sterilization Policies in the US."
[7] Harriet B. Presser, "The Role of Sterilization in Controlling Puerto Rican Fertility," *Population Studies* 23, no. 3 (November 1, 1969): 343–61, https://doi.org/10.1080/00324728.1969.10405290.
[8] Elena R. Gutiérrez and Liza Fuentes, "Population Control by Sterilization: The Cases of Puerto Rican and Mexican-Origin Women in the United States," *Latino(a) Research Review* 7, no. 3 (2010): 85–100.
[9] Stern, "Sterilized in the Name of Public Health."
[10] Jane Lawrence, "The Indian Health Service and the Sterilization of Native American Women," *The American Indian Quarterly* 24, no. 3 (2000): 400–419, https://doi.org/10.1353/aiq.2000.0008.
[11] Lawrence, "The Indian Health Service."
[12] Dana Block-Abraham, Kavita S Arora, and Rebekah E Gee, "Medicaid Consent to Sterilization Forms: Historical, Practical, Ethical, and Advocacy Considerations," *Clinical Obstetrics & Gynecology* 58, no. 2 (2015): 9.
[13] California State Auditor, "Sterilization of Female Inmates: Some Inmates Were Sterilized Unlawfully, and Safeguards Designed to Limit Occurrences of the Procedure Failed: Report 2013-120," June 2014, https://www.auditor.ca.gov/pdfs/reports/2013-120.pdf.
[14] Derek Hawkins, "Tenn. Judge Reprimanded for Offering Reduced Jail Time in Exchange for Sterilization," *Washington Post*, November 21, 2017, https://www.washingtonpost.com/news/morning-mix/wp/2017/11/21/tenn-judge-reprimanded-for-offering-reduced-jail-time-in-exchange-for-sterilization/.
[15] Tom Jackman, "Judge Suggests Drug-Addicted Woman Get Sterilized before Sentencing, and She Does," *Washington Post*, February 8, 2018, https://www.washingtonpost.com/news/true-crime/wp/2018/02/08/judge-suggests-drug-addicted-woman-get-sterilized-before-sentencing-and-she-does/.

procedures.[16] Today, 31 states plus Washington, D.C. have laws allowing forced sterilization of people with disabilities; 17 states allow for the forced sterilization of children with disabilities.[17]

Because the U.S. public health system has a history of conducting such sterilization abuse, it is vital to have strong safeguards against future abuse. As a safety net provider for communities that have experienced this abuse, Planned Parenthood is committed to improving the sterilization consent form so it better secures informed consent. Planned Parenthood believes that an improved consent form will help to prevent future sterilization abuse while facilitating contraceptive access for those who desire it.

II. Planned Parenthood recommends the following ways to enhance the quality, utility, and clarity of the information to be collected.

1. HHS should modify the reading level and visual layout of the consent form to make it more understandable and ensure that the consent patients give is informed.

The current consent form is difficult to understand because of its high reading level and complex visual layout. The consent form is written at a ninth-grade reading level. Researchers who created a lower reading level version of the form found that women who used it better understood the sterilization procedure and the fact that it is irreversible.[18] It is especially important that the reading level of the consent form is accessible because women who use the form are more likely to have less formal education. From 2017–2019, approximately 40% of women aged 22–49 without a high school diploma or GED reported undergoing sterilization, compared to 12% of women with a bachelor's degree or higher.[19] Planned Parenthood urges HHS to modify the reading level of the form to make it understandable to everyone who reads it.

The visual layout of the consent form also makes it difficult to understand. HHS should use larger font size, double spacing, and clearer spacing between form sections. The section of the form that patients fill out, "consent to sterilization," should be made visually more distinct from the other statements on the form. The "Paperwork Reduction Act Statement" may also confuse some patients, as it is not relevant to learning about or consenting to sterilization. HHS should consider removing this statement.

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[16] Caitlin Dickerson, Seth Freed Wessler, and Miriam Jordan, "Immigrants Say They Were Pressured Into Unneeded Surgeries," *The New York Times*, September 29, 2020, https://www.nytimes.com/2020/09/29/us/ice-hysterectomies-surgeries-georgia.html.

[17] National Women's Law Center and Autistic Women & Nonbinary Network, "Forced Sterilization of Disabled People in the United States," January 24, 2022, https://nwlc.org/wp-content/uploads/2022/01/%C6%92.NWLC_SterilizationReport_2021.pdf.

[18] Nikki B. Zite, Sandra J. Philipson, and Lorraine S. Wallace, "Consent to Sterilization Section of the Medicaid-Title XIX Form: Is It Understandable?," *Contraception* 75, no. 4 (April 2007): 256–60, https://doi.org/10.1016/j.contraception.2006.12.015.

[19] Kimberly Daniels and Joyce C. Abma, "Current Contraceptive Status Among Women Aged 15–49: United States, 2017–2019," *National Center for Health Statistics Data Brief*, no. 388 (October 2020), https://www.cdc.gov/nchs/data/databriefs/db388-H.pdf.

2. **HHS should provide alternative format materials and accommodate a supported decision-making process to ensure that all patients can give truly informed consent.**

The underlying regulations at 42 C.F.R. § 50.204(c) stipulate that "suitable arrangements must be made to insure that the information specified [in the consent form] is effectively communicated to any individual to be sterilized who is blind, deaf or otherwise handicapped." We appreciate that HHS requires these accommodations, which are vital to ensure that a community that has historically been targeted by sterilization abuse can give informed consent. Patients may need or prefer a variety of accommodations, including alternative format materials like braille, digitally navigable formats, or sign language videos. The Office of Population Affairs website currently only provides the form for download in English, Spanish, and large-print formats.[20] Planned Parenthood urges HHS to provide these materials in the alternative formats listed above on its websites.

Some patients with disabilities may also need or prefer an alternative process for giving their informed consent. One such process is supported decision-making, which gives people with intellectual and developmental disabilities the chance to consult with a person of their choice to understand the choices they face so they can make their own decisions.[21] This person, known as a supporter, can be a trusted friend, family member, or professional, and helps the person understand their options, ask questions, receive answers, and communicate their own choice. Planned Parenthood encourages HHS to modify the form to allow for supported decision-making processes.

3. **HHS should provide supplementary guidance to providers on how to provide patient-centered and trauma-informed care to help protect patients' ability to give informed consent.**

Planned Parenthood urges HHS to provide supplementary resources to the consent form directed at providers containing best practices for patient-centered care. Such guidance will help ensure that the process of reviewing the consent form is respectful of and responsive to patient preferences, needs, and values, and that patient values guide all clinical decisions.[22] For example, this guidance could include recommendations on how the physical space in which patients review the consent form can be adapted to center patients (e.g., patients may feel more comfortable reviewing the consent form outside of the exam room in a space where they sit at the same level as the provider).

HHS should also develop supplementary guidance for providers on how to review the consent form with patients from a trauma-informed perspective. Some patients reviewing the consent

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[20] Office of Population Affairs, "Key Resources for Title X Grantees," n.d., https://opa.hhs.gov/grant-programs/title-x-service-grants/key-resources-title-x-grantees.
[21] National Resource Center for Supported Decision-Making, "Supported Decision-Making," accessed April 5, 2022, http://www.supporteddecisionmaking.org/.
[22] Agency for Healthcare Research and Quality, "Six Domains of Health Care Quality," November 2018, https://www.ahrq.gov/talkingquality/measures/six-domains.html.

form may have exposure to trauma, including systemic discrimination, violence, and reproductive coercion, that impacts how they give consent for medical care.

4. HHS should lift the mandatory waiting period to allow all people to access sterilization in the same way, regardless of their income or source of insurance coverage.

The underlying regulations at 42 C.F.R. § 50.203(d) impose a 30 day waiting period between the date the consent form is signed and the date of the sterilization procedure. The intent behind the waiting period is well-meant in the wake of decades of federally-funded sterilization abuse. Among people who desire sterilization, however, the impact of the waiting period is a two-tiered system of access, in which people with commercial insurance have immediate access to care and people insured through Medicaid must wait for their health care services.

The ability of people to exercise bodily autonomy—especially people of color and other historically marginalized communities who have faced systemic discrimination—is a key tenet of reproductive justice.[23] As HHS is aware already, there is a traumatic and shameful history of reproductive oppression in our health care system among people of color, people with disabilities, and people with low incomes.[24] This oppression makes it especially hard for these groups to have the same access to services like contraception. The waiting period exacerbates this unequal access to reproductive autonomy and makes contraceptive access less equitable. Protections against sterilization abuse should prevent the medical system from abusing patients, not prevent patients from accessing wanted medical care.

The waiting period was introduced because the medical system failed to protect patients. But its design reinforces negative stereotypes that people insured through Medicaid—who are more likely to be people with low incomes and people of color—are not capable of making decisions in the same time frame as commercially insured patients, who are more likely to have higher incomes and be white. Planned Parenthood strongly urges HHS to conduct new rulemaking to lift the waiting period codified in 42 C.F.R. § 50.203(d).

In addition to being inequitable, the waiting period may be impossible for patients desiring a postpartum sterilization who have a premature delivery. While the regulations at 42 C.F.R. § 50.203(d) allow for the waiting period to be reduced to 72 hours in the case of a premature delivery, the regulations fail to define when a delivery is considered premature. In the absence of a clear definition, states and providers are defining themselves which women (e.g., women delivering before 34 weeks, women delivering before 37 weeks) qualify for the shorter 72 hour

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[23] SisterSong, "Reproductive Justice," accessed April 5, 2022, https://www.sistersong.net/reproductive-justice.

[24] "Executive Order 13985 of Jan 20, 2021, Advancing Racial Equity and Support for Underserved Communities Through the Federal Government," 86 Fed. Reg. 7009 (January 25, 2021), https://www.federalregister.gov/documents/2021/01/25/2021-01753/advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government.

waiting period.[25] This uneven application further demonstrates how the waiting period perpetuates unequal access to sterilization.

5. HHS should modify the consent form to respond to unique barriers posed by the COVID-19 pandemic.

To reduce infectious exposure and conserve personal protective equipment at the start of the COVID-19 pandemic, the Centers for Medicare & Medicaid Services recommended that hospitals cancel or delay elective procedures. The American College of Obstetricians and Gynecologists has a policy designating postpartum sterilization as a nonelective surgery.[26] However, in the absence of federal guidance, some hospitals and state Medicaid agencies have defined postpartum sterilization as an elective surgery, blocking access to care or coverage.[27]

Contraception is an essential form of health care for those who desire it. The consequences of lack of access to sterilization are high, as people may not desire another form of contraception or be able to access it. A study followed women insured through Medicaid who were denied a desired postpartum tubal ligation, due to a problem with their sterilization consent form or the waiting period. The researchers found that 47% experienced a pregnancy in the next year, twice the rate of women who did not request a sterilization.[28] Sterilization denials due to its categorization as an elective surgery may have similar effects. These unintended pregnancies pose health risks to women, worsening the maternal morbidity and mortality crisis in the U.S. that disproportionately impacts women of color.

The use of telemedicine during the COVID-19 pandemic has increased access to health care for many patients. Telemedicine may especially benefit patients that are geographically far from health care providers, or who are unable to travel for appointments due to work or childcare responsibilities. Despite the dramatic increase of telemedicine use during the pandemic, the consent form has not been modified to be compatible with telemedicine visits.[29] Planned Parenthood encourages HHS to modify the consent form to allow for telemedicine oral consents or electronic signatures.

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[25] Kavita Shah Arora, Neko Castleberry, and Jay Schulkin, "Variation in Waiting Period for Medicaid Postpartum Sterilizations: Results of a National Survey of Obstetricians-Gynecologists," *American Journal of Obstetrics and Gynecology* 218, no. 1 (January 2018): 140–41, https://doi.org/10.1016/j.ajog.2017.08.112.

[26] American College of Obstetricians and Gynecologists, "ACOG Committee Opinion Number 827: Access to Postpartum Sterilization," *Obstetrics & Gynecology* 137, no. 6 (June 2021), https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2021/06/access-to-postpartum-sterilization.

[27] Megan L. Evans, Neena Qasba, and Kavita Shah Arora, "COVID-19 Highlights the Policy Barriers and Complexities of Postpartum Sterilization," *Contraception* 103, no. 1 (January 2021): 3–5, https://doi.org/10.1016/j.contraception.2020.10.006.

[28] Andrea Ries Thurman and Torri Janecek, "One-Year Follow-up of Women With Unfulfilled Postpartum Sterilization Requests:," *Obstetrics & Gynecology* 116, no. 5 (November 2010): 1071–77, https://doi.org/10.1097/AOG.0b013e3181f73eaa.

[29] Evans, Qasba, and Shah Arora, "COVID-19 Highlights the Policy Barriers and Complexities of Postpartum Sterilization."

6. **The information collection request does not allow for enough time for meaningful review of public comment before the consent form expires.**

The current consent form is set to expire April 30, 2022, 12 days after the close of this public comment period. Planned Parenthood is concerned that this is not enough time for HHS to meaningfully review the submitted comments, consult with experts in the field of health literacy, patient-centered care, and trauma-informed care, revise the consent form, and notify providers of the new form. If the current consent form must be extended while HHS creates and implements an improved version, the extension period should be no more than 30 days.

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Planned Parenthood applauds the Biden-Harris administration's continued actions to put the health and lives of all people in this country—including women, people of color, young people, people with disabilities, LGBTQ communities, and others accessing services through federal programs—first and foremost. Improving the consent form is a vital action to protect against sterilization abuse and ensure equitable contraceptive access. You are welcome to contact Carmina Bernardo, Senior Director of Public Policy at carmina.bernardo@ppfa.org to discuss our comments. Planned Parenthood looks forward to continuing to work with HHS to ensure that informed consent practices in federal programs are strong and desired reproductive health care is accessible.

Respectfully submitted,

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