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BROCHER SYMPOSIUM: PERSPECTIVES ON ACCESS TO REPRODUCTIVE HEALTHCARE

Comparative preimplantation genetic diagnosis policy in Europe and the USA and its implications for reproductive tourism☆

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Michelle Bayefsky is a medical student at Harvard Medical School. Previously she was a post-baccalaureate fellow in the Department of Bioethics of the National Institutes of Health. Her work in bioethics has focused on issues related to the regulation of genetic testing, the ethical challenges posed by innovations in genetic technology, and questions that arise at the intersection of genetics and reproductive medicine. She is the co-author of Regulating Preimplantation Genetic Diagnosis in the United Sates: The Limits of Unlimited Selection (Bayefsky & Jennings, Palgrave Macmillan 2015).

Abstract Unlike many European nations, the USA has no regulations concerning the use of preimplantation genetic diagnosis (PGD), a technique employed during some fertility treatments to select embryos based on their genes. As such, PGD can and is used for a variety of controversial purposes, including sex selection, selection for children with disabilities such as deafness, and selection for 'saviour siblings' who can serve as tissue donors for sick relatives. The lack of regulation, which is due to particular features of the US political and economic landscape, has ethical and practical implications for patients seeking PGD around the world. This paper contrasts the absence of PGD oversight in the USA with existing PGD policies in Switzerland, Italy, France and the UK. The primary reasons why PGD is not regulated in the USA are addressed, with consideration of factors such as funding for assisted reproductive technology treatmemt and the proximity of PGD to the contentious abortion debate. The obstacles that would need to be overcome in the USA for PGD to be regulated in the future are outlined. Then, the significance of the current divergence in PGD policy for patients around the world are discussed. Regulatory differences create opportunities for reproductive tourism, which result in legal, health and moral challenges. The paper concludes with comments on the need for policymakers around the world to balance respect for the characters and constitutions of their individual countries with appreciation of the needs of infertile patients across the globe.
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KEYWORDS: comparative policy, embryo, preimplantation genetic diagnosis, reproductive tourism, selection

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Introduction

Preimplantation genetic diagnosis (PGD) is a technique which can be employed during fertility treatment to test an embryo's genes before deciding whether to transfer the embryo to a woman's uterus. The technique is primarily used to detect serious heritable disorders, such as Tay-Sachs or cystic fibrosis, which the parents wish to avoid passing on to their children. It can also be used for more controversial purposes, however, such as selecting for a child who can serve as a tissue donor for a sick sibling, selecting for a child with a certain condition, such as deafness, and selecting for a child of a particular sex. In nearly all countries with advanced fertility clinics carrying out PGD, the technique is limited by legal restrictions on its acceptable use. The USA stands apart in its laissez-faire approach towards the use of PGD. Elective sex selection is reported to account for 9% of PGD uses in the USA, and a small number of clinics offer PGD to select for conditions such as deafness and dwarfism (Baruch et al., 2008).

This paper compares the lack of regulatory oversight of PGD in the USA with the regulations in place in Italy, Switzerland, France and the UK. It aims to answer two related questions: what is different about the USA, and what implications does the US approach have for PGD patients globally? To address these questions, this paper analyses the similarities and differences among the national laws in the selected countries and examines medical professional guidelines in the USA. Factors such as the absence of public funding for fertility treatment, the contentiousness of the abortion debate and the relative independence of physicians in the USA are discussed. It also draws upon the scholarly literature on cross-border reproductive care (CBRC) to argue that the lack of regulation in the USA, like other very lenient or stringent policies, helps to foster global reproductive tourism, which poses well-documented health and legal risks for patients and their offspring. Ultimately, it concludes that when creating rules for the use of PGD, policymakers around the world should consider not only the need for laws to reflect the desires and beliefs of their citizenry, but also the very real impact of policies – particularly extremely permissive or strict policies – on patients within their country and abroad.

PGD policy in Europe

There is wide variation in PGD policy in Europe, but a majority of European countries restrict the use of PGD in some way (Soini, 2007). Italy, Switzerland, France and the UK were selected as case studies in order to demonstrate the variation in PGD policy in Europe and the range and types of forces at play in the development of regulations on the acceptable use of PGD.

Italy

In 2004, taking advantage of its unprecedented majority, the Italian Parliament's conservative coalition passed one of the most restrictive laws on assisted reproduction in Europe, Italian Law 40 (Biondi, 2013). The law limited the number of embryos created during IVF to a maximum of three and required that all viable embryos be transferred into the patient's uterus so no embryos would be stored or destroyed. The law also banned the use of PGD and restricted access to assisted reproductive technology to only those with a diagnosis of infertility (Gianaroli et al., 2014), rather than also allowing access to fertile patients with a hereditary condition who need assisted reproductive technology to ensure the birth of unaffected children. Under the restrictive law, PGD was not performed in Italy and Italian couples in need of PGD had to travel abroad for treatment.

Many patients, scientists and members of the general public were opposed to the controversial law, but when a referendum was called in 2005 to have it repealed, only 25.9% of eligible citizens voted, falling short of the 50% needed to meet the quorum. Patient advocates also challenged the law in court and in January 2008 the Regional Administrative Court of Latium declared the ban on PGD unconstitutional (Gianaroli et al., 2014). However, since all embryos, regardless of whether they test positive for the unwanted genetic condition, had to be transferred to the woman's uterus, in practice PGD still could not be carried out. Finally, in May 2009, the Italian Constitutional Court declared that the rule that only three embryos could be created and that all must be transferred was unconstitutional (Molinelli et al., 2012) and PGD began to be performed in Italy once more.

PGD can now be carried out in Italy for purposes aimed at protecting the health and development of the embryo itself – in other words, to prevent the transmission of a hereditary disease. What remains of Law 40 bans 'any form of eugenic selection' or 'breeding techniques … intended to alter the genetic heritage of the embryo or gamete or to predetermine genetic characteristics, except interventions with diagnostic or therapeutic purposes' (2004 (Italy)/2004). There is no formal mechanism for determining what constitutes a sufficiently serious disease to merit PGD, but social uses of PGD, such as sex selection, are prohibited.

Switzerland

From January 2001, Switzerland's legal environment was much like Italy's under Italian Law 40. PGD was prohibited, only three embryos could be created during IVF, and all needed to be transferred. As with Italy, fertility treatment success rates declined and rates of multiple pregnancies increased under the restrictive law (De Geyter, 2012). Switzerland has since changed its law, however. In June 2013, the Federal Counsel sent to Parliament proposed changes that included allowing PGD for serious heritable disorders, allowing eight, rather than three, embryos to be created, and allowing embryo freezing so that not all viable embryos need to be transferred. In December of 2014, Parliament considered the proposed changes and decided to allow the screening of embryos for chromosomal abnormalities (PGS) in addition to PGD for serious heritable conditions. In order for the proposed changes to come into effect, the Swiss needed to amend their Constitution, which required a popular vote. The vote for modifying Switzerland's assisted reproductive technology law took place on June 14, 2015, and 62% of voters decided to allow PGD and PGS (Wurz, 2015). Now in Switzerland, as in Italy,

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