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# Producing Users of Preimplantation Genetic Diagnosis: Dominant and Marginalized Discourses in the US Context<sup>1</sup>

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## Abstract

Preimplantation genetic diagnosis (PGD) is a technique that is paired with in-vitro fertilization to determine which embryos should be implanted in a woman's uterus for gestation. This paper addresses how women using PGD in the United States (US) incorporate this technology into their subjectivities. Analysis of an online bulletin board for PGD users yields that certain components of these women's social identities, namely genetic makeup, age, reproductive history and their desire to be genetic mothers are of prime importance in their understandings of themselves. Facets of social identity related to race / ethnicity, social class and their understandings of health and normalcy are marginalized in these conversations. Disjunctures between representations of PGD users in the press and PGD users' self-representations are of primary concern here.

## Introduction

*Newsweek* and *The New York Times* recently published articles entitled 'Brave New Babies' and 'Screening for Abnormal Embryos Can Offer Hope after Heartbreak'. While science fiction may be the first thing that comes to mind, the topic of these articles is actually preimplantation genetic diagnosis (PGD)—a diagnostic technique that is paired with in-vitro fertilization (IVF) to determine which embryo(s) should be implanted in a woman's uterus for gestation. This technology is at the centre of a growing public debate over the risks and limits of scientific interventions into reproduction and genetics. In the United States (US), this debate has focused on broad social and ethical implications of the use of this technology for sex selection, creating 'designer babies' (babies designed to display specific

traits or characteristics), stem cell research, and the destruction of embryos for scientific or therapeutic reasons.

In American print media, the individuals who are seeking this controversial technology are portrayed in one of two ways. They are either represented as selfish and potentially reckless individuals or as desperately hopeful people who are altruistic in the light of a family tragedy. Articles like 'Brave New Babies' highlight the first view by describing the growth of PGD as a sex selection technique at a handful of clinics in the US, and the desires of potential parents who have a preference for either boys or girls. Other articles depict users of PGD in a sympathetic light, focusing on the plight of parents of gravely sick children. These parents may seek out PGD to screen potential offspring who could provide a therapeutic tissue match or an umbilical cord blood donation to a child already living with a disease or debilitating condition (see for example Tarkan 2005).

The public discourse over whether prospective parents should be able to use PGD to choose the sex of their child and whether 'unwanted' embryos can and should be discarded address crucial social and ethical issues. But do the representations of selfish and reckless or nurturing and altruistic PGD users in the headlines match with users' expectations or experiences of using this technology to conceive and bear children? Positioned as they are at the front lines of the physical, emotional, and moral terrain of reproductive technologies, the women who use PGD are among the most influential in regulating its social life. But their perspectives have been largely absent from debates over the socially acceptable bounds of PGD's usage that privilege the voices of scientists, clinicians, bioethicists, theologians, and legal experts. As one of the primary constituencies invested in PGD, it seems only fitting that the perspectives of PGD users should be better understood and become a part of the public discussions over the social, moral, and individual implications of this technology. It is for this reason that I have undertaken the study of the social life of preimplantation genetic diagnosis.

The central objective of my research is to investigate how those who develop, promote, evaluate and use preimplantation genetic diagnosis conceptualize risk and responsibility. My focus here is on one theme within my research, which is to assess how PGD users construct

their own subjectivities in relation to this technology. Who uses PGD in the US? How do they come to PGD as a reproductive technique? And how do they incorporate this technology into their identities? My analysis indicates that the women's self-representations yield more complex subjectivities than the binary portrayals of PGD users that have appeared in the US popular print media.

My research involves analysis of dialogues in an online bulletin board / support group frequented by women undergoing PGD in the US.<sup>3</sup> The primary purpose of the online bulletin board is to provide a space for people considering and using PGD to share information about and personal struggles with the reproductive difficulties that have led them to PGD and to support each other through the process of assessing and then choosing PGD. I received permission from sixteen women to collect and analyze their postings to the online bulletin board, and I have analyzed their dialogues that appeared over an eighteen month period. These online posts document women's decisions to try PGD as a reproductive intervention and their experiences of undergoing the procedures of IVF, PGD and embryo transfer, and pregnancy.

I chose an online bulletin board for my ethnographic research for what Ann Anagnost (2004, 141) has argued is its usefulness for exploring 'how cyberspace has become a medium for the formation of new kinds of subjectivity and social "space"' and how contemporary subject construction is being transformed in the era of 'web-based modes of knowing'. With attention to the interaction between internet communication and the creation of new forms of affect, my analysis of an online bulletin board reveals how users of PGD are involved in a continual construction of their own subjectivities in relation to this technology.

## PGD users' self-representations

For most people seeking PGD, this is a technique that they come to only after a series of reproductive difficulties or losses, rather than as a first option when deciding to try to become parents. There are five main reasons why women may seek out PGD which have appeared in my research:

known predispositions towards a heritable genetic condition, infertility, 'chromosomal risks' that come along with pregnancy at an 'advanced maternal age', therapeutic tissue matching for an ill child, and sex selection.

On the online bulletin board, the women's narratives build a complex picture of how they arrived at this technology. In contrast to the public portrayals of PGD users, very seldom do individuals seeking sex selection and therapeutic tissue matching appear on the PGD bulletin board. The reasons for this can only be partially explained by my analysis and I will return to this issue shortly. Three overlapping reasons for deciding on PGD dominate the discussions in this online forum: fear of passing along a heritable genetic condition to a child, multiple miscarriages or failed IVF cycles, and 'advanced maternal age' which in the US is considered to be age 35 and above. The original use of the technology was to screen embryos to avoid the transmission of a couple's known genetic predispositions to their children (i.e., X-chromosome-linked diseases; Handside et al. 1990). Now, in addition to the original use of PGD, reproductive endocrinologists or genetic counsellors may recommend PGD as an option for women who have suffered multiple miscarriages or for whom previous fertility treatments (specifically IVF) have failed. Some women seek PGD to rule out aneuploidy, a condition in which either the egg or the sperm provide fewer or more chromosomes than typical. Most often women using PGD for aneuploidy screening are doing so because of the medical association between 'advanced maternal age' and increased risk of 'chromosomal abnormalities' in embryos.

The women who agreed to participate in my study sought PGD for a combination of genetic, chromosomal, and fertility reasons. All of them portrayed themselves on the bulletin board in terms of their medical diagnoses. For a typical example, Sarah<sup>4</sup> introduces herself in the following way on the PGD board:

I did a total of 10 IVF cycles, 5 fresh and 5 Frozen Embryo Transfers. I am currently 42.5 with a 15 month old, my only sustaining pregnancy. I had a total of 3 miscarriages all from IVF cycles, one was chemical, one did not develop a heartbeat and my dear daughter was one of a twin that did not last beyond 8 weeks I think. I did 2 egg retrievals without PGD and after the 2 miscarriages, we were really encouraged to consider PGD. We did 2 fresh cycles with PGD and they both failed, so it

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was on my 3 [sic] PGD cycle that finally worked. Our reproductive endocrinologist gave us consent forms for PGD with our first cycle but we declined. Obviously we did PGD for aneuploidy, I do not have any female issues other than age, but we have pretty severe male factor infertility and because of both our issues, I truly believe that PGD helped our reproductive endocrinologist select the best embryos<sup>5</sup> to transfer.<sup>6</sup>

Narrative constructions of the self on the PGD board follow a fairly uniform format, and highlight similar facets of identity for each woman. The components of the women's social identities which are most important in their self-portrayals on the PGD board are similar to, if not the same as their medical diagnoses. They highlight their genetic risk factors, their age, the number of children they currently have, and their history of reproductive disruption or suffering which has been diagnosed by medical professionals. Married heterosexual partnership is assumed and normative, with most of the participants referring to their male partners as DH, which stands for dear husband, rather than by name. The participants on the bulletin board are almost exclusively women, and this can probably be best explained by the differential physical burdens that women and men experience in infertility treatments, as women's bodies are the site of the bulk of reproductive interventions (Thompson 2005).

Just as the women incorporate medicalized understandings of the body into their narrative constructions of the self, their investment in the importance of genes is noteworthy. Both in their descriptions of themselves as genetic beings, and in their understandings of their embryos as genetic material, their frame of reference regarding the building blocks of kinship and family are imbued with the sense of genes. Women on the board are prone to invoke genetic links with children as an important reason for why they may keep trying to get pregnant with PGD, even if it has been unsuccessful for them in the past. For instance, after a few unsuccessful IVF / PGD cycles, Megan describes this feeling to the group writing: 'Most of us have this dream and assumption that we will have children someday—biological children—and when we get married we picture our children with our husband. It is so hard to let that go.'

The possibility of moving on to parenting options that do not involve a genetic link between the woman and her children is difficult for these women to stomach. The women on the PGD board characterize motherhood

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through adoption and motherhood through donor eggs in the same light—both were shunned for their inability to preserve both a genetic and gestational link between a woman and her children. Amanda recounted this reaction after a second unsuccessful PGD cycle:

I went to my reproductive endocrinologist today and I was so disappointed. I have had 2 IVF / PGD cycles one with 3 normal out of 7 eggs / one with 0 normal out of 6 eggs tested. My reproductive endocrinologist was kinda [sic] trying to talk me into donor eggs (which my husband said he could almost actually see steam coming out of my ears) but I insisted that I did not want to give up yet. The reproductive endocrinologist informed me that I could try again, but if my next cycle is all abnormals I would need to strongly consider donor eggs. I was wondering if anyone out there is in the same boat. I walked out of the office and started bawling, I know I have another chance with PGD, I am just scared that maybe there would not be any normals again.

When Amanda refers to normal eggs here, I can only presume that she is actually referring to embryos, since it is fertilized embryos that are biopsied through PGD and not female egg cells, although the slippage here between eggs and embryos is noteworthy. Amanda and many of her counterparts on the PGD bulletin board actively feminize the responsibility for their reproductive outcomes. So while both the woman's eggs and her male partner's sperm are scrutinized in the PGD process for their 'quality', the genetic and chromosomal analysis is conducted on embryos which consist equally of male and female reproductive material. Even though the embryos are what is tested in PGD, the women often take on the responsibility for the results, particularly if the outcomes are undesirable, blaming the failure of PGD on their 'bad eggs'. Amanda also talks about her cycle of 'abnormals', and here she is referring to her embryos as objects—flawed reproductive material—which is a common construction on the PGD board when the diagnostic outcomes of PGD are negative. These 'abnormals' are no longer considered viable for reproductive purposes, and thus their potential for human subjectivity is denied. On the other hand, the women refer to their embryos as 'embies' before PGD and if the outcomes are desirable. By labelling them 'embies', the women of the PGD board are assigning subjectivity to their embryos, thereby aligning the embryos more with babies than with fertilized egg cells.

In the case of the PGD bulletin board, the women's desire to be genetic and gestational mothers to 'healthy' babies is a strong component of their conceptions of themselves as responsible and nurturing individuals. The primary concern of the women who participated in my study is that PGD holds the potential to find 'strong embryos'—embryos that are genetically and chromosomally 'normal' and hearty enough to withstand life in a petri dish, embryo biopsy, manual transfer to the uterus, and the two-week wait for the pregnancy to 'stick'. These women hope that if an embryo can live through these tests of strength, it will be healthy enough to live through nine months of pregnancy and fulfil their desire to be mothers to healthy babies. The women's accounts of PGD indicate that they feel that PGD allows them to manage their personal reproductive and genetic risks, and in so doing allows them to exercise maternal responsibility through embryonic genetic testing.

The burden of personal responsibility that the women portray on the PGD board is intimately tied to their sense of what it means to be a responsible mother. In this way, PGD users are taking up subject positions as responsible caregivers similarly to women who undergo strict prenatal self-care regimes and other forms of prenatal testing. Feminist theorists in the US and UK have noted how the need for various forms of prenatal testing have been constructed as choices within reproductive medicine, but also as obligatory as 'the standard of care' for certain pregnant women (Lippman 1991; Press et al. 1998; Rapp 1999). Paula Saukko (2004) argues that the various measures that women take during pregnancy in the name of prenatal 'care' can be understood as a part of wider historically gendered regimes of care. In these ways, even from the earliest embryonic stages of human development, the gendering of genomic risk management within pregnancy can be seen as an extension of 'women's traditional labour of love in an increasingly privatized world' (Saukko 2004, 314). As such, prenatal self-care and prenatal testing can be seen as part and parcel of gendered care-giving roles that women take on to provide the best for their children (Press et al. 1998; Rapp 1999; Saukko 2004). As relatively non-invasive prenatal tests like the alpha-feto-protein test or ultrasound testing have become increasingly routinized in prenatal care covered by health insurance, to not partake of these available tests is

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increasingly coming to be seen as technophobic and selfish, if not acts of putting a fetus at risk (Davis-Floyd & Dumit 1998; Lippman 1991; Press et al. 1998).

Similarly, PGD is not only construed as a responsible choice by these women, but also as an obligation. Many of the women on the PGD board express this tension by articulating that they see PGD as one option in a field of difficult reproductive choices, particularly if they are seeking PGD to screen for a heritable genetic condition. When a couple is faced with the choice to 'take their chances' by conceiving naturally or using PGD to rule out the risk of passing along a known genetic predisposition, the women express that the choice is not always clear. By virtue of their presence on the PGD board though, most of the women have felt that trying to conceive without PGD was not worth the risk.

Carlos Novas and Nikolas Rose (2000) have used the term 'technologies of genetic selfhood' to describe the ways in which individuals and families deploy information about their genetic constitution in conduct aimed towards self-improvement considering their genetic conditions or predispositions. These women's constructions of PGD as both a choice and an obligation mark PGD as a technology of the self that both objectifies and subjectifies the women who use it. In the context of prenatal testing, understanding the health of fetuses and of prospective parents in terms of genetic risks and individual obligations is embedded within broader political trends towards neoliberal approaches to various sectors of the political economy (Lemke 2004). While neoliberal political rationalities celebrate individual choice and responsibility, this can easily slide into obligation. Thus while genetic citizens may be actively constructing knowledges and managing genetic risks, the constraints of what constitutes 'genetic responsibility' and narrow definitions of responsible genetic citizenship should not be minimized.

If 'the good subject (...) thus becomes the individual who will modify their lifestyle responsibly in relation to their genetic risk' (Novas & Rose 2000, 495) where genetic risk is defined primarily within the biomedical sphere and the available discourses slide into reproductive decision-making and other life-choices, it may become more clear as to why only certain perspectives on PGD are represented on the bulletin board. The

powerful sentiment of women trying to provide the best chance for their embryos' survival may partially explain why people who seek PGD for sex selection may be un(der)represented on the bulletin board. On the rare occasion when queries regarding sex selection are raised to the board, the reaction of the board participants is largely negative, dismissing the question as frivolous. Sex-selection is an especially sensitive topic amongst a group of women for whom a healthy baby is of the utmost importance. The only exception to this is if a woman is seeking PGD to prevent passing along a sex-chromosome-linked condition, in which case PGD for sex-selection is seen as morally acceptable. Additionally, women who discuss using PGD for a therapeutic tissue match for an ailing child, which gets a similar degree of attention in the popular press as sex-selection, are welcomed into the bulletin board with sympathy for the difficulty of their situations and for the mothers' desire to help the ailing child, but these participants are rare figures on the board and make up a very small minority of the board membership. The distinctions that the women make between themselves and people interested in PGD for 'trivial' reasons establishes a form of gatekeeping within the online community by defining moral boundaries of acceptable usage of this technology, and thus regulating the traffic and content on the message board. By welcoming in some women and their reasons for pursuing PGD while chastising others, the active PGD board members themselves are actively engaged in carving out what constitutes good and responsible genetic citizenship in relation to PGD.

## In the shadow of genetic subjectivities

At the same time as members of the PGD board identify themselves in such a way that accentuates their commonalities in terms of their reproductive and genetic diagnoses and their shared appreciation for the value of motherhood, other facets of their social identities are marginalized or erased from these conversations. Based on what the women write about themselves, there is little way of knowing how they self-identify in terms of racial / ethnic background and socioeconomic class unless these

factor somehow into their PGD treatment plans. For instance, in a discussion of using PGD to detect autosomal recessive genetic disorders, PGD board member Liz was asked how she found out that she and her husband were cystic fibrosis carriers. She shared that when she presented a list of genetic disorders common amongst Ashkenazi Jews to her obstetrician, he told her that it was not worth it to do pre-conception testing for all of the conditions on her list. Later, after a number of failed infertility treatments and miscarriages, additional pre-conception genetic tests were performed and she was surprised to find out that both she and her husband were cystic fibrosis carriers. She recounted with frustration that the full Ashkenazi Jewish panel of genetic tests includes a cystic fibrosis screening, and had they had the full set of tests earlier they would have known of their carrier status and pursued PGD earlier. This is an excellent example of how medical and cultural constructions of the relationships between race / ethnicity and disease reinforce one another (Duster 1990; Kahn 2004). Here one can see that in the medical and scientific spheres a set of diseases have been designated as 'ethnic' and appear together on a Jewish panel of genetic tests. At the same time, Liz makes sense of herself as genetically at risk for passing along cystic fibrosis by attributing her risk factors to her Ashkenazi Jewish heritage. In the space of the PGD bulletin board, genetic subjectivity (in this case 'cystic fibrosis carrier') is always explicit, and may only link to other facets of social identity such as ethnicity if a women sees it as relevant to her medical diagnosis.

Similarly, self-identifications with regard to class and wealth are subsumed within discussions of costs of adding PGD to an IVF cycle. PGD typically costs between \$2000 and \$5000. This is in addition to the costs associated with one IVF cycle in the US, roughly \$8000–\$9000, plus the costs of attendant procedures and medication, which can bring an entire ART pregnancy to \$30,000–\$40,000 (Thompson 2005). These costs would be prohibitive for most working-class and middle-class individuals. Even if individuals have private health insurance, insurers in only fifteen states provide coverage for infertility services (National Conference of State Legislatures 2006), and this coverage does not necessarily include PGD because many insurers consider PGD to be an experimental procedure. Charis Thompson (2005) claims that clinics in the US are primarily concerned

with couples' and individuals' 'ability to pay' for services rendered, which accounts for the high numbers of white, educated, middle- and upper-class, and older clients. Thompson's claim matches up with information from the Center for Disease Control indicating that in the year 2000, the race / ethnicity of ART mothers in the US was 86.2% White, non-Hispanic, 3.6% Black, non-Hispanic, 6.1% Hispanic, and 4.2% Asian (Schieve et al. 2004), which builds support for the case that not only are assisted reproductive technologies exclusive on the basis of ability to pay, but also along the lines of race / ethnicity. There are also transnational classed implications of this being a group of women who are using the Internet as a meeting ground for community building. Haagen et al. (2003) and Novas and Rose (2000) have argued that the demographics of users of private reproductive medicine may be quite similar to the largest demographic of internet users: relatively young, educated, affluent and living in the wealthiest nations in the world. Thus, while women who participate in the PGD bulletin board do not explicitly situate themselves within a class structure, their positionalities as Internet users on the inside of the privatized reproductive medical arena indicate either their ability to pay for services rendered or that they have the social and material resources available to successfully appeal to a private insurance provider that PGD is 'medically necessary'.

Another notable silence from the bulletin board members' characterizations of themselves is any discussion of their understandings of 'health' and 'normalcy' in reference to their embryos. Healthy and normal embryos are characterizations that are taken for granted as net goods on the bulletin board, but what constitutes a healthy or normal embryo is defined in the context of reproductive embryology laboratories. For the most part, PGD users have come to this technology to seek out healthy and normal embryos suitable for sustainable pregnancies, but the values behind this goal are relatively unexamined in the context of the bulletin board. In a scientific sense one might argue that labelling embryos as genetically normal or chromosomally balanced are value-free statements, particularly if they promote 'health', but these labels yield values of health that are circumscribed along genetic lines and that can only be contextualized within the contemporary era of reproductive genetics.

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So we are left with a question: are the components of these women's identities regarding racial / ethnic background, social class and values regarding able-bodiedness unimportant or silenced in the setting of the PGD online forum? Not explicitly, but facets of the women's identities pertaining to their own genetic makeup, biological age and valuation of parenthood gain primacy in this particular setting given its purpose as a support group for people seeking genetic and chromosomal evaluation of their embryos. The stories that these women may tell about themselves in other settings would most likely include other narrative lines. Their positionalities as women using PGD to try to alleviate reproductive difficulties allow them this space to vent and empathize with women in similar situations. It is common to see advice from PGD users with their assessments of the best clinics for PGD and the most successful protocols as well as expressions of gratitude to each other for emotional support through the PGD process. As such, the board serves as a site that both facilitates the growth of lay expertise on genetics and helped to alleviate feelings of isolation in facing reproductive risk.

The women on the PGD online bulletin board are not unique in their preoccupation with their genetic subjectivities. The literature on genetic governmentalities has posited that the Internet serves as a host of new forms of genetic subjectivity by allowing individuals 'translocal engagements' around shared genetic experiences (Heath, Rapp & Taussig 2004), opening up a new space for finding individuals who share their rare genetic conditions, sharing information and contributing to educating one another, drawing on various forms of knowledge of genetic conditions (Heath, Rapp & Taussig 2004; Novas & Rose 2000; Saukko 2004). What does make the PGD bulletin board unique is that rather than sharing a medical diagnosis, the women on the board share the experience of mediating reproductive and genetic risk on behalf of their prospective children.

## Conclusion

At this point what we know about PGD users is that their self-characterizations are more complex than what can be found in American print media.

The sensationalist accounts of PGD users as either selfish or altruistic are reductionist, and do not represent the full range of motivations and experiences of women who seek out this technology. A tangle of factors related to genetic makeup, maternal-age, fertility, and a strong desire for 'their own' children appear to lead women to PGD, most often after a long period of reproductive difficulty and other interventions. Based on existing data on users of reproductive technologies in the US, we can presume that the great majority of the women who participate in the PGD forum are white, educated, and financially able to afford the services, but as these facets of identity are hardly ever revealed in this setting one cannot be certain.

We can surmise that these women define health, wellness, and normalcy for their potential offspring in genetic terms, but we do not know whether they are using definitions provided for them by medical specialists or if they held these definitions prior to pursuing PGD. In order to undergo the physical and emotional rigors of IVF / PGD cycles, these women must have confidence that this reproductive genetic technology holds the solution to their potentially faulty genes and chromosomal contributions that have prevented them from having 'healthy' pregnancies and / or children. In the setting of the PGD bulletin board, genes and biology are ultimately entangled with their identities as would-be mothers, and a degree of gatekeeping enables the women on the board to maintain their positionalities as morally upright users of PGD which distinguishes them from more 'frivolous' users seeking sex-selection.

Popular media outlets provide one of the only sources of information about high-tech reproductive and genetic medicine for the general public. Thus, media reports and commentary can be seen as conduits between scientific research, clinical practice, academic discourse, and the general public. Being that print media outlets are a major source of representation of a range of truths about reproductive genetics for a public audience, reports that media outlets generate should be seen as governmental apparatuses in the Foucauldian sense (Foucault 1991; Rose 1999). The women who use this technology are experts on PGD in their own right who are involved in shaping the bounds of acceptable usage of PGD, thus it seems only fit that the perspectives of women using PGD for a

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wide range of reasons should be better understood and represented in public discourse. PGD users offer perspectives and assessments of PGD that would be especially valuable to its social and legal regulation.

## Notes

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- 2 Correspondence should be addressed to: Michelle McGowan, The Center for Genetic Research Ethics and Law, Case Western Reserve University, School of Medicine, Department of Bioethics, TA 239 10900 Euclid Avenue, Cleveland, OH, USA. Email: michelle.mcgowan@case.edu.
- 3 This research study has been approved by the University of Washington Human Subjects Review Committee. The name and location of the PGD bulletin board has been removed to preserve the anonymity of the individuals who participate in this internet forum.
- 4 Pseudonyms are used in place of the participants' actual names and screen names in order to preserve their anonymity.
- 5 'Embies' is a common term used to refer to embryos on the PGD bulletin board. The significance of this nomenclature will be addressed later in this paper.
- 6 I have corrected misspellings and spelled out common abbreviations used on the bulletin board for clarity.

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