Family Forms Survey: Identifying Donor-Conceived Offspring, Donors, and Recipients in a National Panel

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Abstract: Complicated families, such as those created through gamete donation, deserve scientific study to best understand their experiences and develop evidence-based support. However, research on donor-conceived (DC) offspring has often been stymied by a lack of representative and general samples; samples in this area have often relied on clinical populations and biased means of sampling. Gamete donors have been similarly hard to find, and recipient parents have also often been recruited through self-selected groups. Additionally, given the rise of popular discussion around donor conception in media, greater understanding of public familiarity with DC issues is needed. Thus, our project had two goals 1) assess public familiarity with DC terms and 2) establish the feasibility of identifying DC offspring, gamete donors, and DC recipient parents in a national panel. A total of 5,675 individuals responded to the survey invitation sent to the American Population Panel, and an additional 253 individuals were recruited through social media to assess differences between the modes of recruitment. Within the total group, 100 donor-conceived individuals (either known or suspected), 146 donors, and 147 recipient parents identified themselves; proportions varied between sampling modes. In the full sample, 67% reported being somewhat or very familiar with DC terms. We conclude that both national research panels and social media sources may be viable resources to recruit respondents for research on donor conception, providing an avenue for future studies aimed to generalize findings to wider audiences.

Introduction

Donor-conception (DC) involves gamete (i.e., sperm, egg) donation and embryo donation/adoption, for the purpose of achieving pregnancy in couples or individuals who are experiencing infertility due to medical issues, lifestyle factors, or genetics. Although advances in assisted reproductive technologies (ARTs) are
growing at a rapid pace (Arocho et al., 2019; Gerkowicz et al., 2018), scholars still don’t know how many families utilize ART/infertility services in the United States, due to family-level (e.g., disclosure) and societal-level issues (e.g., lack of public awareness) surrounding donor-conception. Moreover, the increased use in direct-to-consumer (DTC) DNA technology sites, such as 23AndMe, Ancestry.com, etc., have raised questions on ethical and moral grounds such as known versus unknown gamete donation, donor searching (e.g. Pennings, 2019), how donor offspring establish their sense of self and identity (e.g. Ravitsky, 2010), and more.

Before these issues can be addressed, however, we need more information on Americans’ familiarity with, and involvement in third-party reproduction. The focus of the work we describe here was to determine the feasibility and acceptability of using a large national panel and targeted social media advertising to ascertain levels of DC familiarity and involvement. Using national samples such as the American Population Panel (APP) may allow researchers to eventually derive more accurate population estimates of the following groups which have historically been hard to enumerate: 1) donors (i.e., those who have donated or considered donating gametes or embryos), 2) donor recipients (i.e., those who have become pregnant using DC ARTs or parented a child conceived through DC ARTs), and 3) donor-conceived individuals (i.e., those who have been born through DC ARTs). Some prior work suggests this is a viable survey method for donor-conceived young adults (Marquardt et al., 2010), therefore in this study we hoped to replicate this finding and also extend it to the two other subgroups noted above. In surveying a large response base, we can also obtain preliminary evidence of overall DC literacy in U.S. adults, which may become increasingly important given the rising visibility of these practices due to increased DTC DNA testing and media coverage, and decreased secrecy surrounding these forms of fertility help.

**Family Level: Disclosure and Socio-Emotional Aspects of Donor-Conception**

Evidence that national panels are able to not only identify but also survey DC-involved persons opens the door for future research on important topics that have previously been difficult or impossible to study. To understand why, it is helpful to consider what researchers currently can and cannot know about the experiences of offspring and how the practice of disclosure, purposeful and accidental, is associated with individual and family wellbeing.

Parents and/or guardians find it difficult to disclose donor-conception to offspring for several reasons. Some fear they will upset family dynamics, or possibly cause the child distress, either because of the impact of disclosure itself, or through not being able to find the donor (Freeman et al., 2009) The idea that biology is what defines kinship, along with the possibility of damaging the child’s relationship with the social parent(s), keeps many individuals from telling their offspring the truth behind their birth status (Becker et al., 2005). Many parents either delay telling their children, or do not tell them at all, leading to inaccurate numbers of donor-conceived offspring (Gottlieb et al., 2000). A continued delay of disclosure may also contribute to anxiety in parents as they fear accidental disclosure through another route (Applegarth et al., 2016)

With the rise in DTC DNA testing options, there have been many instances of individuals discovering that their family members are, in fact, not related to them (Harper et al., 2016). DTC DNA testing links the information of individuals to others who have used the same service. This practice allows individuals to find and contact their DNA matches, leading them to make connections to biological relatives of whom they had no prior knowledge (e.g. Lozano et al, 2019). As the bank of DNA participants grows from DTC methods, more people are discovering they are donor-conceived, or can connect with children produced
from earlier gamete donation. The effects of this newfound discovery can produce a myriad of emotions ranging from feelings of identity crisis, anger and confusion to relief, happiness and contentment (Jadva et al., 2009). Donor-conceived individuals may encounter mental and emotional issues surrounding their birth status, as well as unique challenges when it comes to knowing their medical and family histories (Rodin et al., 2011; Canzi et al., 2019).

Not all donor-conceived individuals struggle with their origins, but our knowledge comes primarily from prior studies on donor-conception based mainly on convenience samples of those who act on their donor-conception identity by joining social groups or reaching out to donors (e.g. Jadva et al., 2009). Given the nature of this self-selection, we have only a limited understanding of the wide range of reactions that donor-conceived individuals may have to this discovery and, from a policy perspective, are less able to develop appropriate resources to assist offspring and their families with these revelations. Indeed, when a national panel was used to recruit donor-conceived young adults, a varied, and even somewhat negative, picture of attitudes and wellbeing was presented (Marquardt et al., 2010). This is in contrast to the views many self-selected convenience samples of donor-conceived offspring have presented; in example studies, donor-conceived offspring and their parents have individually corroborated that they were well-adjusted and had healthy parent-child relationships following parental disclosure (Golombok, 2020). Adult offspring in self-selected samples such as those drawn from sibling and donor registry websites have sometimes presented a mixed picture, at times explained by age of disclosure of donor conception (Jadva et al., 2009), though the full range of responses may still be suppressed in self-selected samples like that; offspring with no interest in registering for contact are not involved in those studies. Additionally, some individuals may not know for sure that they are donor conceived, but may suspect their conception was not entirely “natural” and seek information regarding this possibility; indeed, the UK-based DonorLink service has noted this feeling of “not fitting in” being a similarity between adopted and donor-conceived offspring (Crawshaw & Marshall, 2008).

Being able to identify and recruit DC offspring from a national panel would be a first step towards recruiting more diverse and more representative samples of offspring. Donors represent even harder-to-track populations and their identification and recruitment would be at least equally valuable in advancing our understanding of donors’ motivations, experiences, their own family lives and identity development as related to being a donor.

**Societal Level: Public Awareness and Familiarity of Donor-Conception**

Despite the rapid advances and usage of ARTs, the topic of donor conception is viewed with some social stigma (Bharadwaj, 2003; Culley et al., 2013; Iltis & Cherry, 2015). This is most likely due to the fact that it breaks culturally conceptualized boundaries by including a third party. In general, reporting and sharing of one’s personal experiences with donor conception is not widespread, possibly due to fear of social disapproval (Nordqvist, 2014). Greater public awareness of DC issues and reduced stigma of infertility may aid the individuals and families considering various paths to parenthood, as exposure to knowledge about ART and personal contact with those who have used infertility treatments seem to reduce concern and increase utilization of these services (e.g. Greil et al., 2013; Greil et al., 2017).

A reduction of stigma and better general knowledge around donor conception could be beneficial for at least three main reasons. First, couples and individuals who are having difficulties conceiving may feel more comfortable seeking help (Greil et al., 2013). Second, it may also help parents feel more able to inform their donor-conceived children about their biological background (Nachtigall et al., 1998). Third,
greater awareness would help mental health professionals understand the unique challenges donor-conceived individuals face when it comes to identity consolidation and navigating complex family relationships (Turner & Coyle, 2000).

**Current Study**

The current study is primarily exploratory with several goals, not least of which is to establish the feasibility of our approach to identify and recruit a larger sample of DC offspring, parents and donors in the future. Are we able to use a large U.S. national panel for this purpose? That is, could DC-involved people be found in a source of respondents not originally recruited for this intent? To further establish feasibility, we additionally ran a recruitment effort through a more targeted social media approach, which may be more akin to self-selected and targeting sampling strategies used in prior studies. If our recruitment efforts from the generalized panel are successful, and these efforts uncover a sufficiently large accessible population of DC-involved people, national panels and outreach efforts like these may prove viable for future research on the more generalized experiences and needs of these individuals. Recruitment via these two very different approaches additionally provides an opportunity to explore how knowledge and experiences of the two groups may diverge. Finally, we aim to provide preliminary information regarding overall DC literacy among a national sample. Given the estimated and projected growth in the use of these methods in the U.S., gaining information on the general public’s knowledge of these issues should also prove fruitful for both research and educational efforts that seek to improve the experiences of all involved.

**Methods and Data**

**Sample**

The first sample was drawn from the ongoing American Population Panel (APP), designed and administered by the Center for Human Resource Research (CHRR) at The Ohio State University. The APP is a panel of adult US residents who have agreed to take part in research surveys sent to them via email, text or regular mail, or by being telephoned if that is their preference. The panel was started by CHRR in July 2017 and continues to grow through a variety of traditional and non-traditional in-person, online, telephone and email recruitment methods. The APP is not a random sample, though it can be weighted for representativeness to some populations given the appropriate parameters and resources. That is a longer-term goal of this project; in the meantime, we elected to focus on detailing the possibilities of recruitment through these two methods as a baseline for future research ideas. Therefore, some groups may be overrepresented in unweighted responses like the current study, such as female respondents.

Currently, the APP has approximately 47,000 respondents although they numbered 37,000 at the time of this survey. Respondents who were already part of the panel had previously provided their birth year, sex, zip code, education level, and race/ethnicity - characteristics that are used to target respondents for particular surveys and which are available for all studies. For this survey, all APP members were invited to participate through their previously-established preferred method of contact.

More than 50 projects have been completed to date using the APP. Some, like the current survey, have consisted of only a few questions and were sent out to all panel members, or all panelists residing in particular geographical areas, who could choose to answer and be entered into a raffle to win a gift card (Gavazzi and Gee, 2021). Others have been much longer paid surveys sent to subsets of panelists to meet specific quotas like the National Sports and Society Survey (Allison and Knoester, 2021; Knoester and
In addition to using APP members, targeted ads were also used to recruit additional survey respondents to participate in the minisurvey through social media. These ads appeared on social media sites tagged with keywords appropriate to the topic. Respondents recruited through the targeted social media ads were first asked if they were already APP members and if so, they were re-directed to enter the survey via their own unique APP link. Non APP members were then presented the questions from the minisurvey plus additional demographic questions on sex, highest level of education attained, their State of residency and their race/ethnicity. They were asked if they wanted to sign up into the panel and only if they said yes were they asked for their zip code.

As an incentive to participate, respondents were entered into a raffle for a $25 gift card (40 total cards). Due to requirements of the project’s funder (institution of the lead author), respondents were asked if they were a current employee of the funder when they entered the survey. If they were, they were ineligible for the incentive but were invited to participate regardless. IRB approval was granted to the institution collecting the data, and IRB reliance was granted by the institution housing the lead author.

Minisurvey

All respondents were invited to answer the survey questions shown in Appendix 1. These questions were developed to be concise in length but broad in nature in an effort to simply identify the presence of people who have been involved with ART, and assess general public familiarity with the terms used. Questions were developed through a literature search in this area, prior research efforts, and individual experiences within the research team. They were then refined through conversations with the research team’s contacts who were donor-conceived, a former gamete donor, and donor recipient parents, as well as feedback from those who do not identify as any of those groups to assess generalized familiarity and comfort with question wording and presentation.

Quality Control

Various quality checks were performed by CHRR to ensure that, in the case of the APP, only panelists were invited to answer the survey and that members could only answer it once (a unique survey invitation is sent to each panelist which cannot be copied and used by anyone else). CHRR staff also ran post-survey checks on IP addresses to ensure they only came from within the US, and took a close look at email addresses. Respondents were contacted if their information didn’t match up with answers they had given on prior surveys or when signing up into the APP. It is more difficult to prevent non-panelists from answering the survey multiple times, but again there were various checks in place such as a “captcha” set of letters that must be typed in prior to answering any survey. CHRR researchers also looked carefully at all responses and pulled out any surveys that were uploaded very close to each other in time, especially when they took the same amount of time to complete. Put another way, most non-panel cases were human checked after the fact and decisions then made to keep or drop their data.

Prior to fielding a survey, CHRR also runs it through a simulator to check for programming errors and then each survey is tested by members of the CHRR testing team who check skip patterns and look for spelling errors etc. CHRR also runs timing checks on surveys so that very short surveys which could signal satisficing can be pulled out for extra scrutiny and potential removal from the database. All of these
checks were performed on the data in this mini-survey and resulting cases passed quality assurance checks.

**Analysis Plan**

Our aim with this survey was to see if donor conceived individuals, donors, and donor-recipient parents could be identified in a national panel through panel invitations; additionally, other respondents were recruited via social media advertisements for comparison. Because of the non-representative nature of both sampling strategies and the variance in sample size (the social media sample being much smaller), data were analyzed descriptively, focusing on proportions and frequencies of responses. Data cleaning and analysis were completed in Stata17. Missing data were treated as responses when informative or deleted if not instructive. Responses with fewer than 5 respondents were masked for privacy concerns and are indicated in tables as + when proportions are reported. Pearson’s $\chi^2$ was used to evaluate differences in categories in responses by mode of sample.

Although demographic variables were limited, they do provide some contextual information regarding the make-up of the sample. Gender was coded as male, female, and other/non-binary combined. Generation was coded by year of birth: 1926-1959, 1960-1979, and 1980-2003. Education refers to the highest level achieved and was coded as having a Bachelor’s Degree or more versus less than a Bachelor’s Degree, which includes “other” educational statuses. Region (of current residence) was coded as West, Midwest, South, and Northeast according to U.S. Census Regions.

**Results**

This study yielded results pertaining to knowledge of donor-conceived offspring, donors, and recipients in the United States, plus showed the feasibility of using panels like the APP alongside social media campaigns to recruit hard-to-sample populations like donor-conceived individuals and donors.

Invitations went out to all 37,000 APP members plus we ran survey recruitment advertisements on Facebook and Reddit. A total of 6,452 Panelists responded to the invitation, but 777 didn’t finish the survey – 343 stopped at the consent statement and an additional 50 got no further than the UVU employment question. A total of 5,675 panelists provided answers to all survey questions. In addition, 218 respondents who completed the survey were recruited via Facebook and 44 via Reddit. A total of 5,937 therefore completed our survey. CHRR found some social media recruits that also answered as APP members, and some surveys were suspiciously short. Nine cases were therefore screened out leaving 5,928 valid responses in total, of which 5,675 were from the original APP panel and 253 were from social media recruitment.

**Demographics**

Demographics of the two samples are shown in Table 1. The APP sample was 72% female identified, 25% male identified, and 3% nonbinary or other gender, and the social media sample was similar at 75% female, 23% male, and 2% other or nonbinary ($\chi^2 = 1.18, p > 0.05$). One-third (33%) of the panel sample were born between 1926 and 1959, 38% between 1960 and 1979, and 29% between 1980 and 2003; in contrast, the social media sample was significantly younger, with only 18% born in the earliest years, 30% between 1960 and 1979, and 52% in the most recent generation ($\chi^2 = 62.86, p < 0.001$). Sixteen percent
of APP respondents were living in the Western region, 40% in the Midwest, 30% in the South, and 14% in the Northeast. Social media respondents were slightly differently located, with 22% in the West, 23% in the Midwest, 36% in the South, and 19% in the Northeast ($\chi^2 = 28.47, p < 0.001$). Both samples were approximately split on college education: 46% had not received a bachelor’s degree in the APP sample, compared to 49% in the social media respondents ($\chi^2 = 0.75, p > 0.05$).

Donor Conceived Statuses

One of the primary purposes of this project was to understand if donor conception involved (offspring, donors, recipient parents) could be identified in a general panel. As a closer analog to the self-selected and clinical samples of the past, we also collected these statuses among the social media group. Table 2 shows proportions of status responses among the two samples. Respondents with some variation of the three statuses were significantly more likely to be found among the social media respondents than the panel, however, the panel responses were not devoid of these statuses. Of the 253 panel respondents, nearly 6% were some kind of known or suspected donor-conceived offspring; however, this amounted to only 15 total respondents. Contrast this with the panel respondents, where only 1.5% of respondents identified as knowing or suspecting they were donor-conceived, but this amounted to 85 individual respondents. Interestingly, an additional 1.11% of panel respondents stated that they “didn’t know” if they were donor conceived. As discussed later, this unique response may be informative and worthy of further exploration, which may be possible in a generalized sample such as this.

Further exploring the status results, 5.14% of the social media sample identified as donors; in the panel

| Table 1. Demographics of Sample by Sampling Type. N = 5,928. Percentage by column and variable. Fewer than 5 respondents masked as +. |
|-------------------------------------------------|-------------------|-----------------|
| **Generation***                                | Panel             | Social Media    |
| 1925-1959                                      | 33%               | 18%             |
| 1960-1979                                      | 38%               | 30%             |
| 1980-2003                                      | 29%               | 52%             |
| **Region***                                    |                   |                 |
| West                                           | 16%               | 22%             |
| Midwest                                        | 40%               | 23%             |
| South                                          | 30%               | 36%             |
| Northeast                                      | 14%               | 19%             |
| **Education**                                  |                   |                 |
| Less than college                              | 46%               | 49%             |
| College or more                                | 54%               | 51%             |
| Missing                                        | +                 | 0%              |

* $p < 0.001$ on $\chi^2$ test of differences between categories using pairwise deletion.*
2.34% did, which was still more total respondents, of course. In the social media sample, 9.49% of respondents identified themselves as recipient parents, whereas 2.17% of the panel did. Again, although a smaller proportion of the panel sample endorsed these identities, this broader sampling scheme produced a larger overall sample, resulting in more individuals with the identity in the data. This could open possibilities for future studies that may explore these identities and related experiences in more detail among a more generalized population than has been studied in the past.

### Familiarity with Donor Conception

Finally, a further goal of this study was to collect preliminary data to ascertain familiarity with terms related to donor conception among general respondents. Table 3 depicts these results in the data, which are unweighted and cannot be extrapolated to larger populations accordingly. Overall, 13% of respondents were very familiar, 54% of individuals were somewhat familiar, and 22% were not very familiar with the DC terms we used. Only 10% of the sample had heard of ARTs but did not know about them, and fewer than 1% had never heard the terms before. When examined by sample type, as expected, those recruited through targeted ads on social media were more likely to be very familiar with the terms ($\chi^2 = 65.80, p < 0.001$). Further demographic descriptions of familiarity are shown in the table. Familiarity with these terms varied by gender ($\chi^2 = 59.70, p < 0.001$), region ($\chi^2 = 26.12, p < 0.01$), and education ($\chi^2 = 61.71, p < 0.001$). As might be expected, familiarity also varied significantly by all three donor-conception related statuses (offspring $\chi^2 = 135.51, p < 0.001$; donor $\chi^2 = 82.59, p < 0.001$; recipient parent $\chi^2 = 331.86, p < 0.001$), however, small numbers in those cross-tabulated cells resulted in potentially inflated test results.
Discussion

The results of this study suggest two things: having at least a base level of familiarity with donor conception seems to be common, and both national survey panels and targeted social media ads may be a viable path to sampling donor conceived individuals, gamete donors, and recipient parents, replicating and extending prior attempts of this nature (Marquardt et al., 2010). Both of these findings are potentially good news for both the individuals involved in donor conception and researchers looking to further study these populations. On the side of the individuals, greater familiarity with these technologies may be due, in part, to greater exposure to families discovering donor conception through at-home DNA testing (Pennings, 2019) and recent (related) media examples of donor conception (e.g. Shapiro, 2019). Over half of our sample said that they were somewhat or very familiar with these terms. Greater general familiarity and discussion of these issues may help decrease the stigma and disapproval felt by families created this way (Nordqvist, 2014). This may contribute not only to individual well-being and willingness to seek help (Greil et al., 2013; Greil et al., 2017) but also to a greater willingness of parents and children to have conversations around what this method of conception means for their relationships (Nachtigall et al., 1998).

Furthermore, we successfully identified 100 potentially donor-conceived individuals (who reported various levels of certainty regarding their conception) and 146 donors, as well as 147 parents of donor-conceived individuals. This replicates the usefulness of strategies like these for finding donor-conceived individuals (Marquardt et al., 2010) and further suggests that other parties involved in these family forms, particularly donors themselves, may be reachable through large enough generalized invitations. All told, 4.2% of the panel respondents were any sort of donor conceived, donor, or recipient, whereas much higher proportions of the social media sample were: 12.2% of Facebook respondents and 32.5% of Reddit respondents. This makes sense, given the targeting of the ads compared to the generalized nature of the
invitation to the existing panel, and future work may consider using ads like this to recruit into panels for additional studies. Particular attention may need to be paid to individuals who are unsure of their donor-conceived status (both "suspecting" and outright saying they “don’t’ know” about their status) (Crawshaw & Marshall, 2008) and further study of these individuals may provide insight into the ways in which parents who struggle to tell their children outright of their conception (Applegarth et al., 2016) may subtly give information in this regard.

Further targeting panel members who are likely to belong to these groups (such as by focusing on particular gender identities or regions of residence) may be an additional way to increase sample sizes and produce more generalizable studies than those completed on samples recruited directly from clinics or donor-conception-specific groups or websites, which may be inherently biased towards individuals who feel more strongly about their conception or involvement in DC issues than the population in general. Further research like this is needed to understand both the positive and potentially negative experiences of these individuals.

Limitations

At the time of this survey the APP consisted of approximately 37,000 registrants. Our survey was opened by approximately 17% of potential respondents and fully answered by just over 15%. It is important to note that surveys of this type (sent to all respondents without unique follow-up and with only raffle incentives instead of direct payment) have generally received smaller response rates than would be expected of a more targeted and paid survey opportunity in the APP (and larger survey pools are likely to have smaller sample sizes too; Wu et al., 2022). In fact, responses to this minisurvey were consistent with other minisurveys sent out around the same time, particularly when considering topic (Personal calculations of final author, APP Director):

- September 2020 (Theme: voting): 5,685
- September 2020 (COVID19): 5,372
- October 2020 (international relations): 1,739
- February 2021 (COVID19): 6,421
- May 2021 (climate change): 5,114.

With larger incentives and a more concerted effort to gain responses, even more individuals from the subgroups of particular interest to this study might have been located. Further, the demographic and contextual variables in this preliminary study were limited. In the future, data collection can include additional information to provide more descriptive accounts of who these individuals, and thus help to paint a fuller picture of the people involved plus allow for more representative samples.

Conclusion

With a large enough invitation pool, hard-to-reach populations like donor-conceived individuals, donors, and recipient parents may be reachable through panel samples, perhaps even combined with social media targeted ads to supplement some groups. This research is likely to only become more important as the use of ART (Gerkowicz et al., 2018), and potentially other third-party techniques (Arocho et al., 2019) continues to grow. Researchers should take advantage of willing respondent pools and consider how unique recruitment or question phrasing may continue to yield interesting, useful data in this area.
Appendix 1: Minisurvey questions

References


