Social Media as a Tool to Engage and Enroll Underrepresented Populations in Digital Health Research Studies

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Abstract

Background: Emerging digital health research poses additional roadblocks to the inclusion of historically marginalized populations in research. Alternative methods of accessing and engaging under-resourced communities may aid in achieving long-term sustainability of diversified participation in digital health research.

Objective: The aim of this paper is: 1) to characterize the socioeconomic and demographic differences in individuals who enrolled and engaged with different remote, digital and traditional recruitment methods into a digital health pregnancy study; and 2) to determine if social media outreach is an efficient way of recruiting and retaining specific underrepresented populations (URPs) in digital health research.

Methods: The Better Understanding the Metamorphosis of Pregnancy (BUMP) study was used as a case example. The BUMP study is a prospective observational cohort study utilizing digital health technology to increase understanding of pregnancy in a sample of 524 women, aged 18-40 in the U.S. The BUMP study employed different recruitment strategies including: a patient portal for genetic testing results, social media platforms (e.g. Facebook, Reddit, Instagram) via paid and unpaid ads, a community health organization providing care to pregnant women (Moses/Weitzman Health System), and other methods.

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Paid social media ads provided access to and enrollment of a diverse potential participant pool of race/ethnic-based URPs in comparison to other digital recruitment channels. Of those that engaged with study materials, paid social media recruitment had the highest % of non-White (Non-Hispanic) respondents (26.5%, n=85/321), in comparison to unpaid social media: Facebook and Reddit (22.2%, n=37/167). Of those that enrolled in the study, paid social media also had the highest % of non-White (Non-Hispanic) participants (20.0%, n=14/70), compared to unpaid social media (15.4%, n=8/52) and genetic testing service subscribers (18.8%, n=72/384).

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Conclusions: Paid and unpaid social media recruitment provide access to various URPs and allow for similar levels of sustained study retention in varying degrees, with different strengths and weaknesses for each methodology. URPs showed lower retention rates than their white counterparts across outreach methods. Community-based recruitment methods were associated with lower participant engagement, enrollment and retention compared to other recruitment methods used. These findings suggest unknown roadblocks to engagement of URP via more traditional methods, and suggests the need for more tailored research on converting engagement to enrollment and retention for URPs via social media methods to bridge this divide.

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Conclusion: Paid and unpaid social media recruitment provide access to various URPs and allow for similar levels of sustained study retention in varying degrees, with different strengths and weaknesses for each methodology. URPs showed lower retention rates than their white counterparts across outreach methods. Community-based recruitment methods were associated with lower participant engagement, enrollment and retention compared to other recruitment methods used. These findings suggest unknown roadblocks to engagement of URP via more traditional methods, and suggests the need for more tailored research on converting engagement to enrollment and retention for URPs via social media methods to bridge this divide.

Key Words: digital health research; digital health technology; DHT; recruitment; research subjects;

pregnancy; maternal health; underrepresented populations; health equity

Introduction

Background

Participation in research studies by historically marginalized populations, particularly racial and ethnic minority groups, is significantly lower compared to their White counterparts. This has resulted in underrepresentation of these groups across research study disciplines[1-3]. The National Institutes of Health (NIH) defines underrepresented populations (URPs) as those with disproportionately low representation relative to their overall or disease-specific population[4]. Despite mandates to include these groups in federally funded research, factors such as general attitudes towards research, sociocultural barriers, and accessibility continue to hinder diversity in research populations[1,5-11]. Certain URPs, such as African Americans, face additional historical and structural barriers to research participation including low health literacy, lack of access to care, and mistrust of institutions[2].

Lack of engagement and enrollment of URPs in research studies has and continues to contribute to health disparities within specific population sub-groups. These health inequities are especially visible in pregnant populations, as illustrated by present maternal health outcome statistics[12]. Since 2019, the maternal mortality rate in the U.S has continued to rise steadily, jumping to 32.9 deaths per 100,000 live births in 2021, compared with a rate of 20.1 in 2019[12]. For pregnant women of ethnic or racial minorities, this discrepancy in maternal health outcomes is hyper-visible. The historical exclusion of pregnant women from research studies has been present due to a perceived concern of lack of direct participant benefit or risk of significant harm to offspring. This exclusion has resulted in gaps in scientific knowledge regarding key women's health issues that further exacerbate women's health outcome disparities[13].

The use of digital health technologies (DHTs) in digital research studies (e.g. smartphones, wearable devices or other digital products, electronic health records (EHR), and telehealth options) continues to rapidly evolve, altering how these technologies are used to support individual and population health research[14,15]. DHTs and virtual research studies present the potential to mitigate existing gaps in healthcare access, quality of care, and healthcare outcomes– especially amongst URPs. However, the presence of a 'digital divide'– which refers to the patterns of difference in utilization of technology, the internet and social media by race, ethnicity, and/or socioeconomic status, etc.– exemplifies yet another barrier to participation and engagement for URPs in digital health research[16-18].

As these roadblocks to participation continue to be observed, additional efforts are also necessary to identify successful evidence-based enrollment strategies for reaching and engaging URPs, especially in digital research studies. Current engagement and recruitment strategies of URPs often emphasize outreach via community-forward channels (e.g. partnerships with community leaders, churches, community-based clinic sites and other organizations) to alleviate some of the barriers of mistrust present in these communities[10]. However, conflicting evidence exists regarding the effectiveness of community outreach as an isolated strategy for increasing enrollment of URPs[10]. Another suggested recruitment strategy to bolster engagement and involvement of URPs in studies is social media advertising. More recently, social media has been utilized by researchers as a new source of participant recruitment and may be an especially useful tool in locating specific URPs due to: the widespread reach of social media to potential participants who otherwise might have been not visible to researchers, the anonymity that social media provides users, and general mistrust of healthcare institutions and more traditional recruitment methods by URPs[2, 19-20].

Over the past decade, social media use in the U.S has steadily increased. As of 2022, over 300 million people in the U.S. use social media, making the U.S. home to the third largest social media audience globally[21,22]. The social media platforms Facebook, Twitter, and Instagram account for a combined ~83% of all social media site visits in the United States[21]. As nearly three quarters of Americans report social media use, social media platforms now provide researchers a new, accessible alternative to traditional recruitment methods (e.g. printed flyers, in-person outreach) to meet individuals where they are, and help bridge the digital divide[23].

The 'digital divide' is two-fold. The use of DHTs requires ownership of devices (e.g. smartphones, wearable devices), adequate internet access, and a level of digital and health literacy, indicating the presence of additional cost and other barriers to digital health engagement and use of DHTs[18]. These barriers disproportionately impact those from socioeconomically disadvantaged backgrounds[17,18,24]. The other key component of the 'digital divide' is the disconnect in engagement, especially among URPs. Although social media usage for racially-underrepresented populations continues to surpass that of their White counterparts, these populations are significantly

less likely to engage with health information on the internet and social media, or utilize social networking channels to learn more about their health[24-26]. However, studies indicate expressed interest by specific URPs (e.g. African American women) in utilizing DHTs and social media to engage with health information[27-29]. This further suggests that social media may be a powerful, untapped resource in reaching and engaging URPs in DHT research studies and digital health[26].

Prior Work

Existing research studies have primarily used Facebook as a means of recruiting URPs, especially for stigmatized groups, but few research studies explore the feasibility and effectiveness of utilizing other social media platforms and recruitment methods specifically to engage URPs in digital health studies[17]. The use of more nuanced social media outreach methods– such as advertisements on Instagram (a platform which has nearly 127.2 million active users in the U.S. as of 2023)– to recruit and engage URPs in research studies is still in its infancy[22].

Goal of This Paper

This paper aims to: 1) characterize the socioeconomic and demographic differences among individuals who enrolled and participated in a US-based pregnancy study: The Better Understanding the Metamorphosis of Pregnancy (BUMP) study through various remote, digital, and traditional recruitment methods; and 2) to determine whether social media outreach is an effective means of recruiting and retaining historically URPs to participate in pregnancy-related digital health research.

Methods

Overview

The BUMP (Better Understanding the Metamorphosis of Pregnancy) study is a prospective observational cohort study conducted by 4YouandMe, a non-profit organization that pilots open source, digital health research. The aim of the BUMP study is to leverage DHTs in the collection of objective and subjective measurements of health to increase understanding of pregnancy and subsequent complications in a sample of women, ages 18-40 in the U.S. (n=524)[30]. The first participant was enrolled in the BUMP study on February 23, 2021, and the last participant completed the study on July 1, 2023. Participants were enrolled over a 6-12 month period, and followed for up to 16 months.

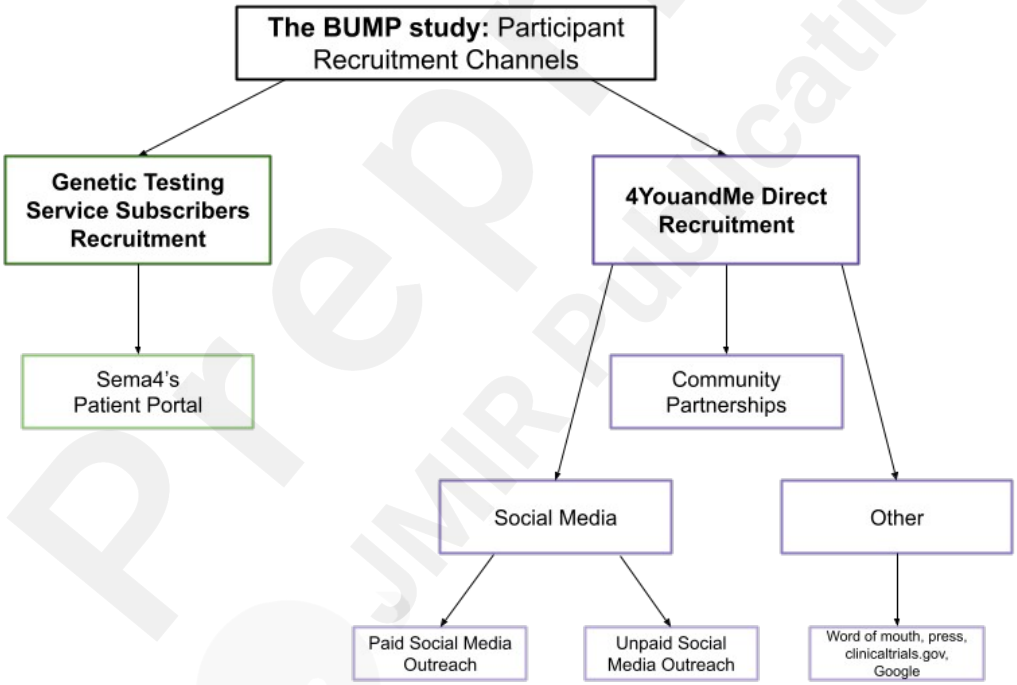
The BUMP study employed various recruitment methods, including: a patient portal for genetic testing results during pregnancy, social media platforms like Facebook, Reddit, and Instagram through both paid and unpaid advertisements, in-person clinics at a trusted community health center offering prenatal and postnatal care, as well as other outreach strategies such as word of mouth and participant referrals. Data were collected through surveys and active tasks on an app, wearable DHTs (e.g. a Garmin smartwatch, an Oura smartring and a Bodyport smart scale) and patients' electronic medical records (EMR). The BUMP study was approved by the institutional review board (IRB), Advarra (Pro00047893). Details of the BUMP study are described in external publications[30].

Recruitment

Recruitment for the BUMP study was primarily conducted via two methods: Genetic testing service subscribers recruitment (Sema4) and 4YouandMe direct recruitment. Genetic testing service subscribers recruitment includes outreach to subscribers to genetic testing via Sema4's patient portal. 4YouandMe direct recruitment consists of 3 recruitment sub-outlets: social media (including both

paid and unpaid outreach), community partnerships and other (e.g. word of mouth, press, clinicaltrials.gov, etc.). (Figure 1).

Figure 1. Flowchart of recruitment channels for The BUMP study.



Genetic Testing Service Subscribers Recruitment (Sema4)

Primary recruitment for the BUMP study was completed via Sema4's patient portal, specifically focusing on those that signed up to receive results of genetic testing results during pregnancy. Sema4's patient portal combines mobile health (mHealth) and electronic health (eHealth) as it provides a mechanism for Sema4 to engage with its patients via communication of test results and management of electronic consents[30]. Patients who consented to having their EMR data accessed by Sema4, and those requesting results of genetic testing or other tests commonly associated with pregnancy, received an email from Sema4 with information about the BUMP study[29].

4YouandMe Direct Recruitment (Social Media Recruitment, Community Partnerships, Other)

All recruitment conducted by methods other than outreach to genetic testing service subscribers via Sema4's patient portal of genetic-testing subscribers are referred to as 4YouandMe direct recruitment. 4YouandMe direct recruitment was conducted primarily through social media platforms (e.g. Facebook, Reddit, Instagram, etc.).

Unpaid Social Media Outreach (Social media Recruitment)

Social media sites with moderated group forums related to pregnancy (e.g. Facebook and Reddit) were the focus of unpaid social media recruitment efforts to reach the wider population of all study-eligible pregnant women for the BUMP study. The BUMP study staff conducted outreach efforts with forum and group moderators in order to gain permission to post fliers on these forums. The BUMP study staff monitored public response to the live group and forum posts, and interacted with moderators and interested individuals by answering questions and engaging with posted content. The goal was to build trust and credibility within these online communities, while mitigating some of the noted common challenges faced in social media-based recruitment.

Text study descriptions and image-heavy digital recruitment fliers were utilized to reach potential participants, and posted as both standalone and response posts in various pregnancy-related online forums (e.g., "Pregnant Women's Group" and "Mom's Talk: Pregnancy to Toddler" on Facebook; and "Science Based Parenting," "Pregnant," "Mommit," and monthly 'BUMP Groups' i.e., "January 2023 BUMP Group" on Reddit). (Multimedia Appendix 1-4).

Paid Social Media Outreach (Social media Recruitment)

A digital recruitment flier was posted on 4YouandMe's personal Instagram profile, and its visibility was boosted via Instagram's paid promotion feature, which allows you to select a 'goal' (i.e. driving traffic to a specific website). The total spend for paid social media recruitment was $1,939.30 over several paid Instagram advertisements.

Interested participants in the BUMP study were able to click on the ad, and were then guided directly to complete the online study interest form, hosted on the secure electronic data capture (EDC) platform, REDCap. The advertisement parameters for the paid social media outreach method included women, aged 18-42, currently living in the U.S.; and women, aged 18-36, living in the lowest ~10% of U.S. zip codes by per capita income.

Community-based Recruitment/Outreach (Community Partnerships)

Community-based partnerships were formed with Moses/Weitzman Health System, a large federally qualified health center that works to deliver comprehensive healthcare services to those in need throughout the state of Connecticut. Partnership costs were covered by an agreed-upon fee for collaboration between Moses/Weitzman Health System and 4YouandMe. Medical Assistants at three locations (Meriden, Middletown and Clinton) that provide prenatal and postnatal care, were educated by the BUMP study staff on the study overview, goals, eligibility requirements, wearable DHT use, and participant expectations. Moses/Weitzman Health System staff members were also provided with printed recruitment materials for the BUMP study.

Eligible potential participants were informed about the BUMP study by Moses/Weitzman Health System staff during one of their initial prenatal visits. Potential participants that expressed interest in the BUMP study were given a printed flier, tailored to outreach of this specific community, with a scannable QR code linking interested participants to the online study interest form, as well as contact

information for study staff available to answer any questions prior to providing any personal information. (Multimedia Appendix 5-6).

Other Recruitment Sources (Other)

Additional recruitment for the 4YouandMe direct outreach method was completed by other avenues such as: referrals from current BUMP study participants to friends, family and colleagues, general word of mouth about the BUMP study, articles published about 4YouandMe and the BUMP study on the Oura Ring blog and in STAT Magazine, and other sources such as Google, and clinicaltrials.gov.

Statistical Analysis

Engagement, for the purpose of this analysis, is defined by any interaction by a potential participant with the BUMP study material such as clicking on an advertisement, or filling out a study interest form. Engagement with study advertisements from social media sites was tracked by Google Analytics, and REDCap was utilized to monitor completed study interest forms and collect additional information regarding recruitment channels. Due to the nature of recruitment conducted of genetic-testing service subscribers via Sema4's patient portal, engagement was unable to be calculated for this group. Enrollment is defined as any participant who signed the informed consent and officially enrolled into the study, for any duration of time. Whereas retention refers to participants who completed the full study period through birth– or at least 9 months.

Engagement, enrollment and retention rates were stratified by different recruitment channels and race. Sociodemographic characteristics including age, race/ethnicity and income per capita (USD) by zip code were compared across different recruitment channels. Enrolled participants were also asked to share their home zip code upon enrollment. Participant's zip codes were used to calculate the distribution of per capita income of enrolled study participants, stratified by their recruitment method. All analyses were conducted utilizing Excel v.16.0.

Results

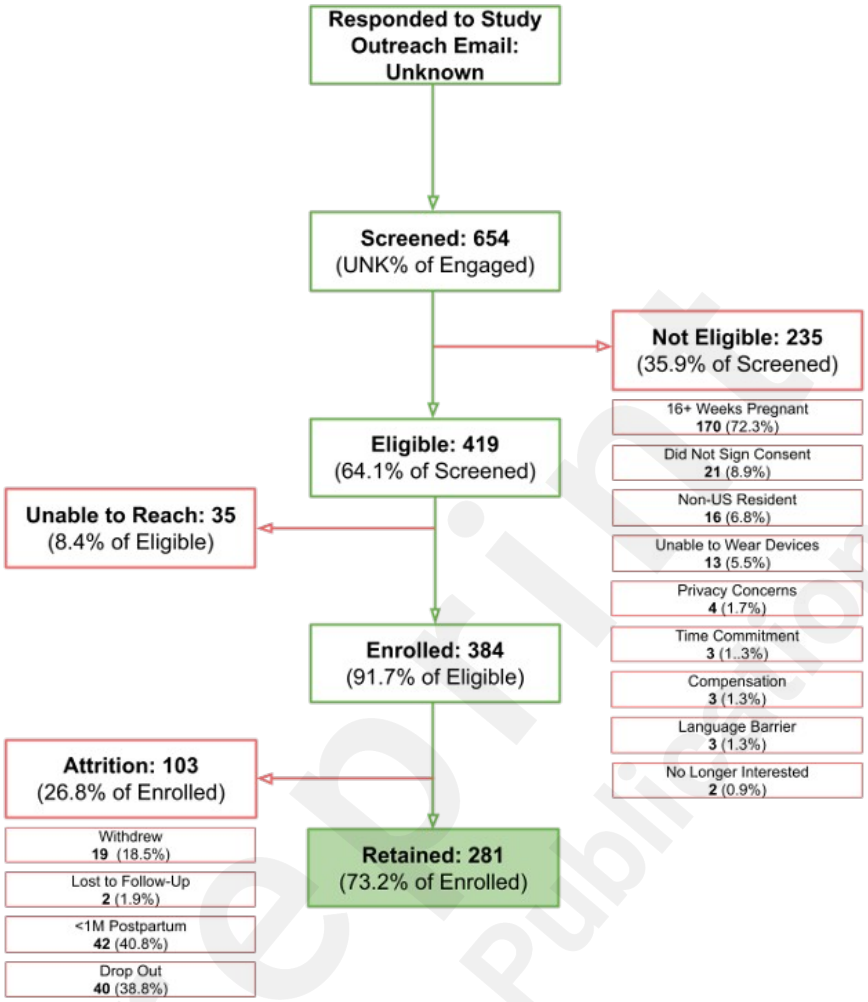
Engagement, Enrollment and Retention

Across all recruitment channels, 524 pregnant participants were enrolled into the BUMP study and 379 (72.3%) completed the full study period. 384 (73.3%) participants were recruited via Sema4's portal for genetic testing service subscribers, and 140 (26.7%) participants were recruited to 4YouandMe directly from the other recruitment approaches. Participants recruited via Sema4's patient portal (genetic testing service subscribers) had similar rates of study retention as those recruited via unpaid social media (Reddit and Facebook) and paid social media (Instagram). Moses/ Weitzman Health System had the lowest percentage of study retention.

Genetic testing service subscribers recruitment was conducted via Sema4's patient portal for genetic testing service subscribers. Engagement data for this group is unknown. Of those that responded to an initial email with information about the BUMP study, 654 participants completed a screening call with a study coordinator. Of this group, 64.1% (n=419) met eligibility criteria, and 91.7% (n=384) of eligible participants enrolled in the study, resulting in 73.2% (n=281) of participants retained for the full study. (Figure 2).

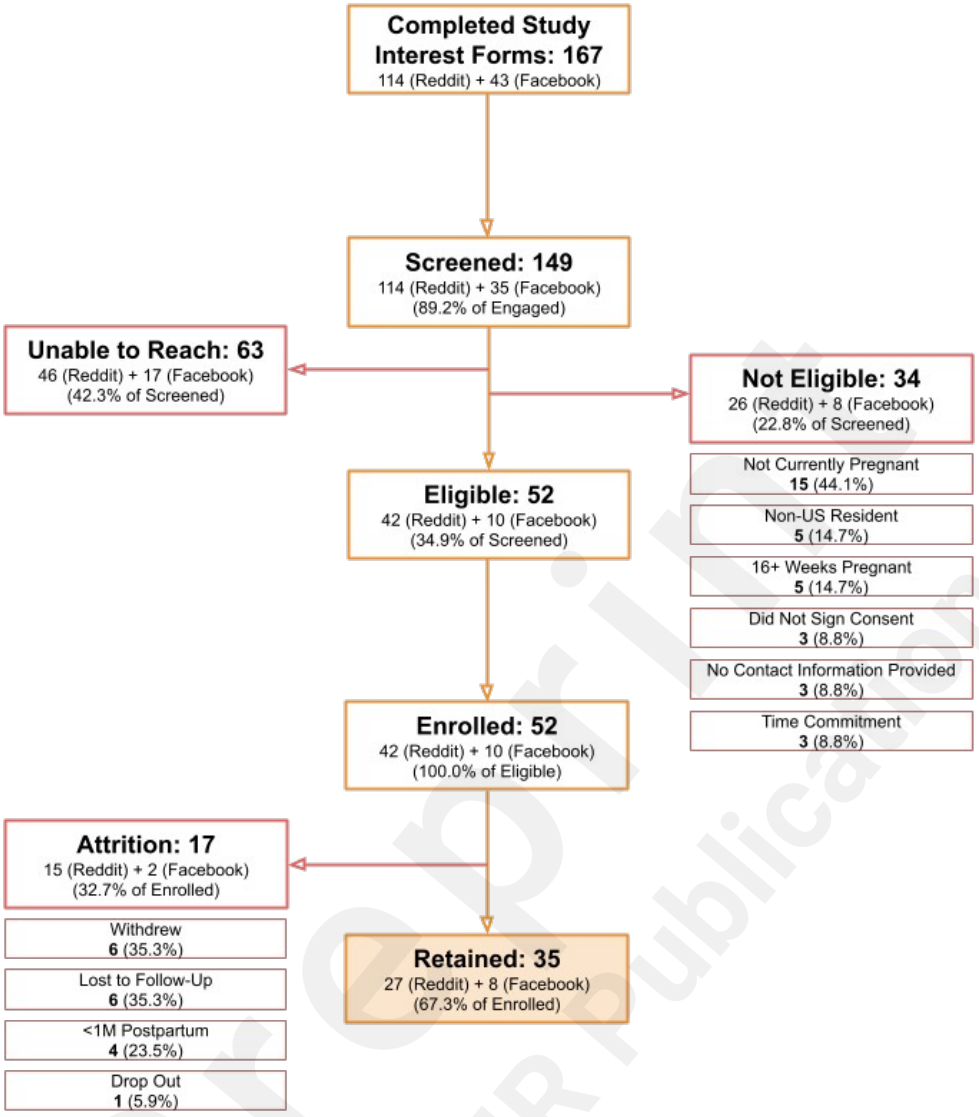
Figure 2. Engagement, enrollment and retention for the BUMP study from outreach via genetic

testing service subscribers (Sema4).



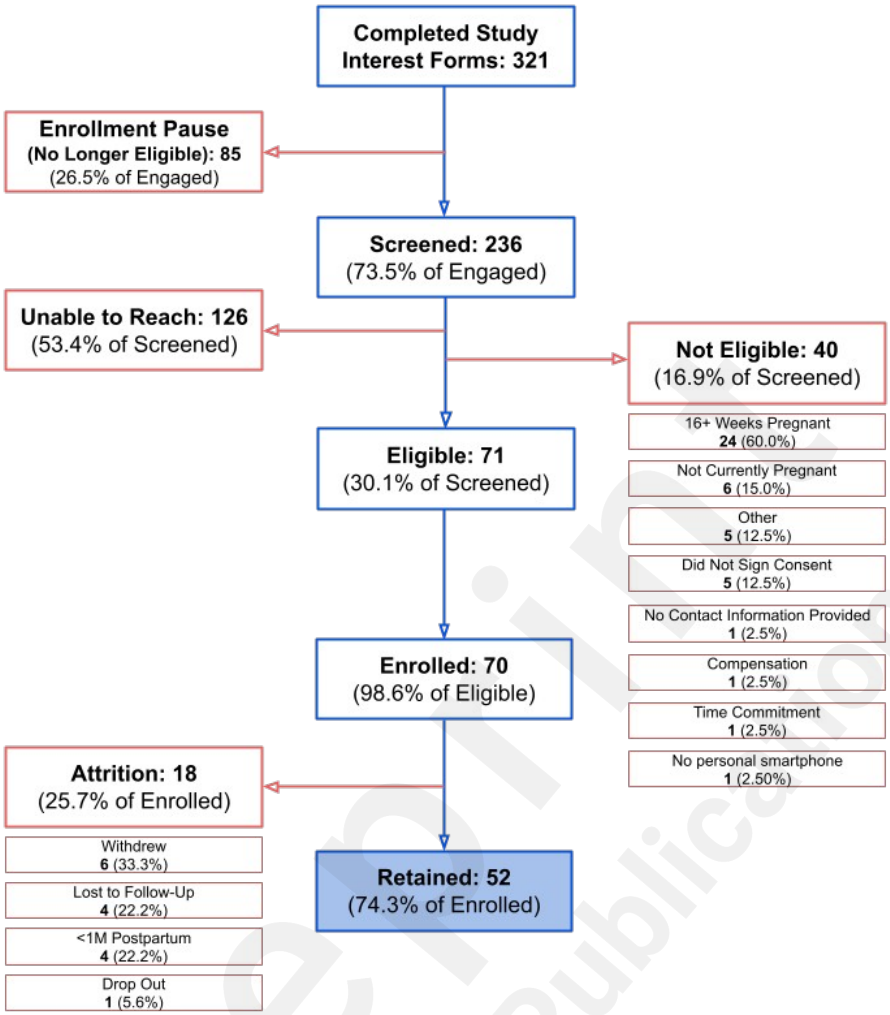
Social media recruitment of participants was conducted via unpaid advertisements (Reddit and Facebook) and paid advertisements (Instagram). Of those that engaged with an unpaid ad posted on Reddit and Facebook (n=223), 74.9% completed a study interest form (n=167). Of this group, 31.1% (n=52) met eligibility criteria, and 100.0% (n=52) of eligible participants enrolled in the study, resulting in 67.3% (n=35) retained by the study's end. (Figure 3).

Figure 3. Engagement, enrollment and retention for the BUMP study from outreach via unpaid social media recruitment (Reddit and Facebook).



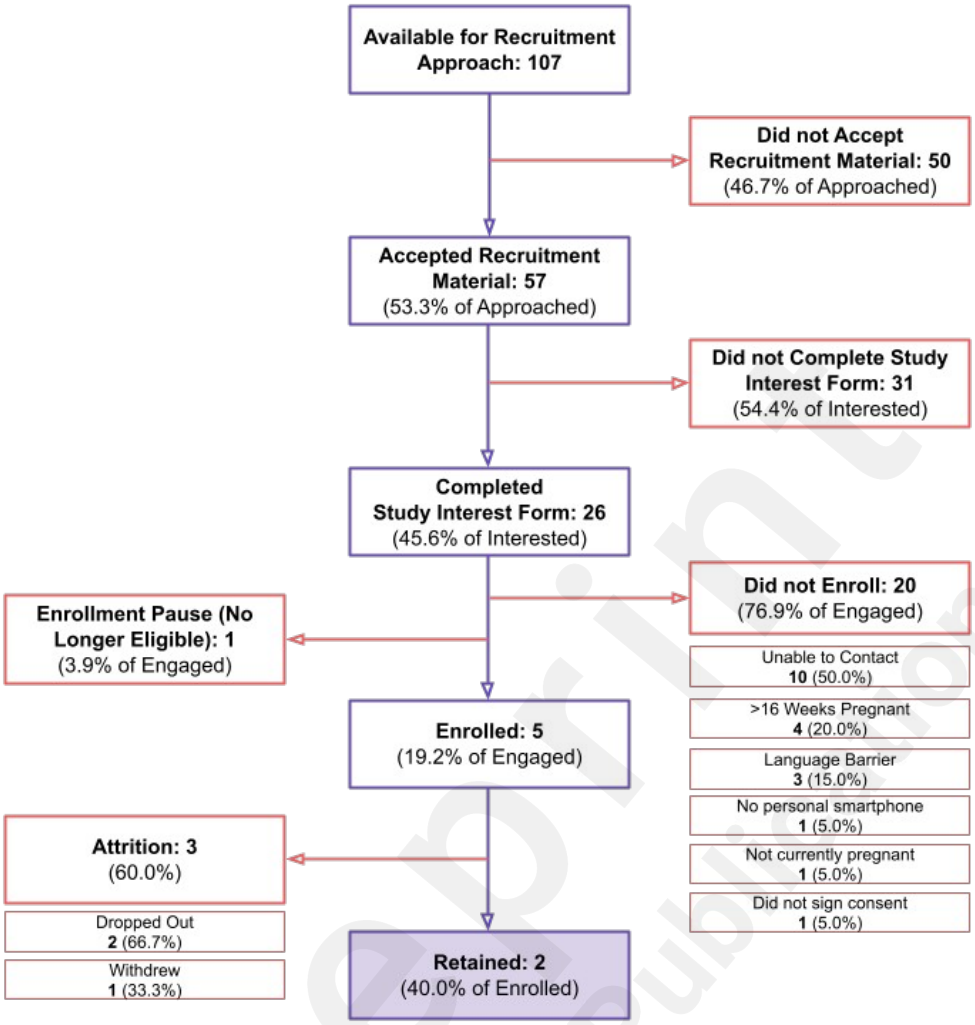
For individuals recruited from paid social media ads on Instagram, 321 individuals completed study interest forms, of those, 26.5% (n=85) were not eligible for enrollment as a result of a study-wide enrollment pause due to high recruitment volume. These individuals were notified of the enrollment pause, but were not re-contacted for further enrollment. Of the remaining 71 eligible participants, 98.6% (n=70) enrolled in the study, and 74.3% of enrolled (n=52) were retained. (Figure 4).

Figure 4. Engagement, enrollment and retention for the BUMP study from outreach via paid social media recruitment (Instagram).



Of participants recruited via in-person visits with their clinician at a community health center providing affordable prenatal care (Moses/Weitzman Health System), 107 met eligibility criteria and were able to be approached on site by staff. Of those approached, 24.3% (n=26) engaged with study material by completing the study interest form. 76.9% (n=20) of participants did not enroll for a variety of reasons such as: unable to contact (10), 16+ weeks pregnant (4), language barrier (3: 2 Spanish, 1 Haitian Creole), no personal smartphone (1), not currently pregnant (1), or did not sign the consent (1). 1 participant was no longer eligible due to the previously-mentioned study-wide enrollment pause. 5 participants ultimately enrolled in the study, and 40.0% (n=2) were retained, the lowest retention rate of any utilized recruitment method. (Figure 5).

Figure 5. Engagement, enrollment and retention for the BUMP study from outreach via Moses/Weitzman Health System.



Over a 25-week period of active advertisements on both paid and unpaid social media channels (excluding community partnerships and other methods) 491 study interest forms were completed (total n=594, including all 4YouandMe direct recruitment outlets). This resulted in 122 enrolled participants (total from 4YouandMe direct recruitment, n=140) via paid and unpaid social media recruitment into the BUMP study.

Table 1. Engagement and enrollment characteristics across different social media channels.

	Unpaid advertisements (Reddit)	Unpaid advertisements (Facebook)	Paid advertisements (Instagram)
Ad Reach	n/a	n/a	97,475
Website/Ad Taps	197	26	1,534

Completed Study Interest Forms	124	43	324
Participants Enrolled	42	10	70
Start-End Date	4/5/22 - 9/8/22	5/18/22 - 9/8/22	9/2/22 - 10/19/22

Characteristics of the Cohort

The majority of enrolled participants in the BUMP study (n=524) were between the ages of 26-35 years (69.3%, n=363), and White non-Hispanic (72.7%, n=381). For those that engaged with materials via 4YouandMe direct recruitment, participants were asked “Where did you hear about the BUMP study?” and were also given the option to self-identify both their race and ethnicity. Of participants that responded via each recruitment outlet (Reddit: n=124, Moses/Weitzman Health System: n=26, Instagram: n=321) Reddit had the highest percentage of White non-Hispanic potential participants (79.0%, n=98), while Moses/Weitzman Health System had the lowest percentage of White non-Hispanic potential participants (26.9%, n=7) and the highest relative percentage of Black potential participants (19.2%, n=5), followed by Instagram (9.9%, n=32).

Table 2. Characteristics of the cohort among those who engaged (ENG) with recruitment materials, enrolled (ENR), and were retained (RTD) in the BUMP study. [a]

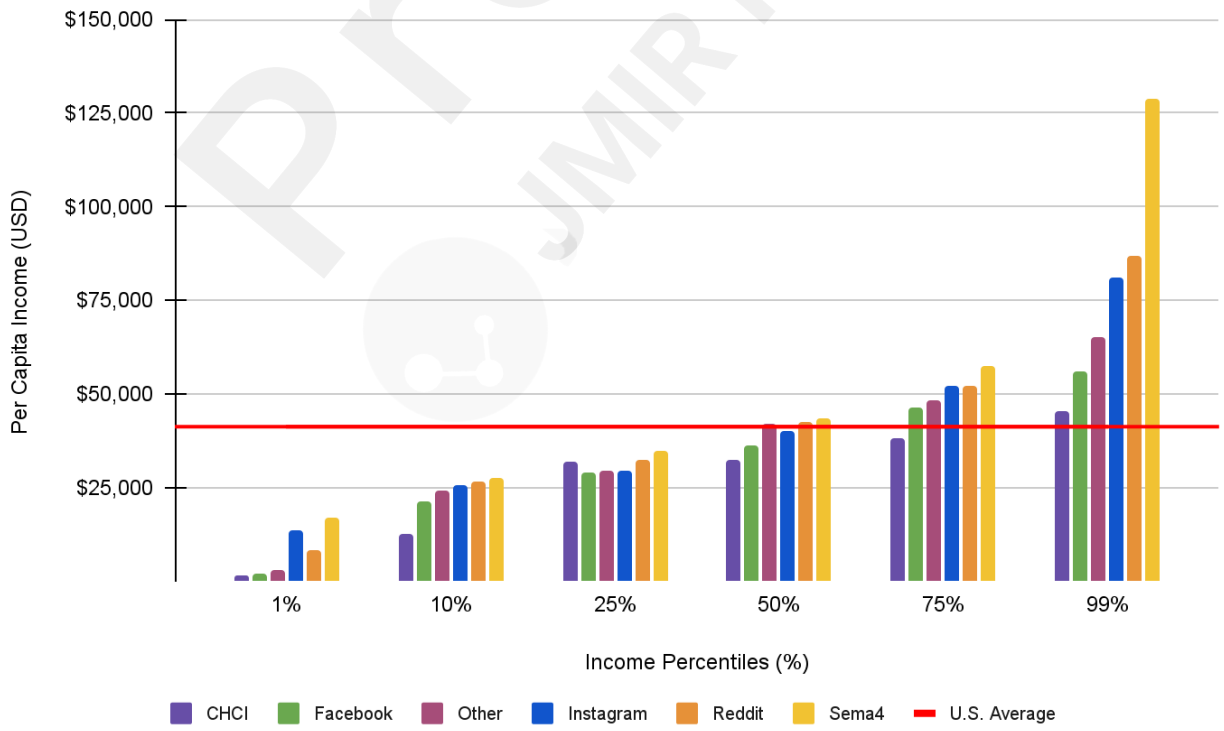
[a] Values for participants recruited by other methods are included in (Multimedia Appendix 7).

	Genetic Testing Subscribers Recruitment		4YouandMe Direct Recruitment											
	SEMA4		Instagram			Facebook			Reddit			Moses/Weitzman Health System		
	ENR (n=384)	RTD (n=281)	ENG (n=321)	ENR (n=70)	RTD (n=52)	ENG (n=43)	ENR (n=10)	RTD (n=8)	ENG (n=124)	ENR (n=42)	RTD (n=27)	ENG (n=26)	ENR (n=5)	RTD (n=2)
Age (years)														
18-25	18 (4.7%)	10 (3.6%)	40 (12.5%)	1 (1.4%)	1 (1.9%)	4 (9.3%)	1 (10.0%)	1 (12.5%)	5 (4.0%)	1 (2.4%)	1 (3.7%)	8 (30.8%)	0 (0.0%)	0 (0.0%)
26-35	251 (65.4%)	187 (66.6%)	224 (69.8%)	56 (80.0%)	42 (80.8%)	35 (81.4%)	7 (70.0%)	6 (75.0%)	102 (82.3%)	34 (80.9%)	20 (74.0%)	16 (61.5%)	4 (80.0%)	2 (100.0%)
36-45	115 (29.9%)	84 (29.9%)	57 (17.8%)	13 (18.6%)	9 (17.3%)	4 (9.3%)	2 (20.0%)	1 (12.5%)	17 (13.7%)	7 (16.7%)	6 (22.2%)	2 (7.7%)	1 (20.0%)	0 (0.0%)

Race														
Black	15 (3.9%)	10 (66.7%)	32 (9.9%)	2 (2.9%)	1 (50.0%)	4 (9.3%)	0 (0.0%)	0 (0.0%)	4 (3.2%)	1 (2.4%)	1 (3.7%)	5 (19.2%)	1 (20.0%)	1 (50.0%)
White (Non-Hispanic)	274 (71.4%)	213 (77.7%)	215 (66.9%)	52 (74.3%)	40 (76.9%)	28 (65.1%)	9 (90.0%)	7 (87.5%)	98 (79.0%)	34 (80.9%)	22 (81.5%)	7 (26.9%)	2 (40.0%)	1 (50.0%)
White (Hispanic)	4 (1.0%)	1 (25.0%)	18 (5.6%)	3 (4.3%)	2 (66.7%)	2 (4.7%)	0 (0.0%)	0 (0.0%)	5 (4.0%)	0 (0.0%)	0 (0.0%)	5 (19.2%)	1 (20.0%)	0 (0.0%)
Asian	35 (9.1%)	26 (74.3%)	16 (4.9%)	4 (4.29%)	2 (66.7%)	1 (2.3%)	0 (0.0%)	0 (0.0%)	9 (7.3%)	5 (11.9%)	3 (11.1%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
Native or Indigenous American	0 (0.0%)	0 (0.0%)	1 (0.3%)	0 (0.0%)	0 (0.0%)	1 (2.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (3.9%)	0 (0.0%)	0 (0.0%)
Native Hawaiian or Pacific Islander	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	1 (2.3%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
More than one race	18 (4.7%)	13 (72.2%)	18 (5.6%)	5 (7.1%)	3 (60.0%)	4 (9.3%)	0 (0.0%)	0 (0.0%)	6 (4.8%)	2 (4.8%)	1 (3.7%)	2 (7.7%)	0 (0.0%)	0 (0.0%)
Unknown or Not reported	38 (9.9%)	18 (47.4%)	21 (6.5%)	5 (7.1%)	4 (80.0%)	2 (4.7%)	1 (10.0%)	1 (12.5%)	2 (1.6%)	0 (0.0%)	0 (0.0%)	6 (23.0%)	1 (20.0%)	0 (0.0%)
Ethnicity														
Hispanic or Latino	12 (3.1%)	6 (2.1%)	36 (11.2%)	5 (7.1%)	4 (7.7%)	4 (9.3%)	0 (0.0%)	0 (0.0%)	7 (5.7%)	0 (0.0%)	0 (0.0%)	13 (50.0%)	3 (60.0%)	1 (50.0%)
Not Hispanic or Latino	372 (96.9%)	275 (97.9%)	276 (85.9%)	63 (90.0%)	47 (90.8%)	39 (90.7%)	10 (100.0%)	8 (100.0%)	114 (91.9%)	42 (100.0%)	27 (100.0%)	13 (50.0%)	2 (40.0%)	1 (50.0%)
Unknown or Not reported	0 (0.0%)	0 (0.0%)	9 (2.8%)	2 (2.9%)	1 (1.9%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	3 (2.4%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)

Those recruited via Sema4 (genetic testing service subscribers) had the highest participant income per capita by zip code at nearly every income percentile. Participants recruited via community outreach partnerships (Moses/Weitzman Health System) had the lowest number of participants in the 50-99th percentiles of per capita income by zip code, study wide. (Figure 6).

Figure 6. Distribution of income per capita (USD) by zip code of enrolled participants in the BUMP study by recruitment method. (N=384, N=140 respectively).



Discussion

Principal Results

The results of this analysis suggest that the use of social media (paid and unpaid ads) as a tool to engage, enroll and retain URPs in digital health pregnancy research can be effective. Unpaid social media proved to be successful, low-cost, and achieved the highest engagement- to-enrollment rate among all approaches used by the 4YouandMe direct recruitment channel. However, maintaining successful recruitment on these platforms required significant sustained effort and time from the study team. Paid social media ads on Instagram also effectively reached and engaged pregnant women as an URP in digital health research. Paid advertisements were a low study team lift, but incurred a cost – over 25 weeks, $1,939.30 was spent on Instagram ads, resulting in 70 enrollments, or $27.70 per enrolled participant.

Participants recruited via paid social media (Instagram) showed the highest overall retention rate as 74.3% (n=52/70) of participants enrolled completed the full study period. This suggests that paid social media outreach was more effective in engaging and retaining study participants than other recruitment methods. This outreach method was even more effective than recruiting through genetic testing service subscribers (Sema4), where participants may have had a higher intrinsic motivation to participate and stay in the study due to a potential prior interest in genetic testing and related research.

Paid social media recruitment also facilitated the widespread engagement and enrollment of URPs. Paid recruitment had a higher proportion of non-White, Non-Hispanic respondents that engaged with the BUMP study and enrolled, in comparison to unpaid social media. Retention of non-White, Non-Hispanic participants was low across all recruitment methods.

Recruitment via social media (including paid and unpaid recruitment) also provided access to and enrollment of a different socioeconomic population than those enrolled via genetic-testing service subscribers (Sema4) recruitment. Enrolled participants from this group had significantly higher per capita incomes, exceeding $75,000 USD– far surpassing the U.S. national average income per capita[31]. In contrast, enrolled participants from social media recruitment and community-based outreach's highest average per capita incomes were $74,771.15 and $45,401.00, respectively. From this we may infer that recruitment via social media (and community partnerships) also facilitated the increased enrollment of socioeconomic-based URPs.

Community-based partnerships for BUMP study recruitment revealed unique and informative data trends. Over a 24-week period at three Moses/Weitzman Health System clinics which serve a large underrepresented population, only 53.3% (n=57/107) accepted recruitment materials, showing hesitancy to engage in research studies even when the information is conveyed by trusted healthcare providers or their staff. Of those who accepted the materials, only 8.8% (n=5/57) enrolled in the study.

Community health center-recruited participants also showcased population-specific barriers such as: language barriers, and not owning a personal smartphone. Ultimately, despite efforts from the BUMP study team and Moses/Weitzman Health System staff, recruitment flow, engagement, and enrollment remained challenging, further highlighting known difficulties in steady streams of recruitment among URPs recruited solely via community-outreach outlets.

Limitations

Due to methodology of recruitment and outreach for the BUMP study via genetic testing service subscribers (Sema4), overall study interest and engagement was unable to be followed in the same manner as 4YouandMe direct recruitment avenues. Similarly, demographic information (e.g. race/ethnicity, socioeconomic status, etc.) were not provided for interested or potential participants from this group, limiting the comparison in engagement with study materials by various URPs between recruitment of genetic testing service subscribers and social media and other methods.

Furthermore, several limitations were present in recruiting for the general pregnant population via social media platforms. We were unable to discern how many of the total reached population was actually pregnant or study-eligible, this was particularly relevant for paid social media outreach and recruitment. For paid social media outreach we relied on inputting the lowest ~10% of U.S. zip codes by per capita income in order to increase our socioeconomic diversity, however it is unknown if zip codes are too narrow of a parameter for focused Instagram ads.

True study engagement to enrollment statistics were further limited by the presence of a study enrollment pause, due to high-volume of completed study interest forms and potential participants. This enrollment pause rendered 132 participants no longer eligible (NLE) for study participation. Without this pause, the engagement-to-enrollment rate may have reached 44.5%. Recruitment for the BUMP study via the various 4YouandMe direct approaches was not conducted for the entire study duration, impacting overall ability to assess engagement to enrollment effectiveness. Finally, the small size of this study sample (n=524) indicates the need for larger, similar studies to further validate the trends observed.

Conclusions

Social media and virtual outreach is both an emerging and exciting tool that researchers can utilize to engage and recruit various URPs to participate in digital health research studies, specifically about pregnancy. Paid social media advertisements provide unique, innovative, and low time-burden opportunities for researchers to engage and interact with a larger volume of underrepresented communities in comparison to traditional recruitment methods.

Though commonly perceived as the gold-standard for outreach to URPs, community-based partnerships, even when used in conjunction with other outreach methods, did not provide a smooth, consistent path to outreach, engagement, or retention of URPs in digital health research. This lower-engagement and retention indicates the need for further tailored strategies of addressing additional barriers to sustained participation in digital health studies for URPs beyond mistrust, lack of engagement or information and access, to better bridge the ‘digital divide’ and engage URPs to ensure equitable access to digital health research and DHTs.

Acknowledgements

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BUMP study participants for their time, effort and contributions to this research.

Conflicts of Interest

None declared.

Abbreviations

BUMP: Better Understanding the Metamorphosis of Pregnancy
DHT(s): Digital health technologies
EMR: Electronic medical record(s)
URP(s): Underrepresented population(s)

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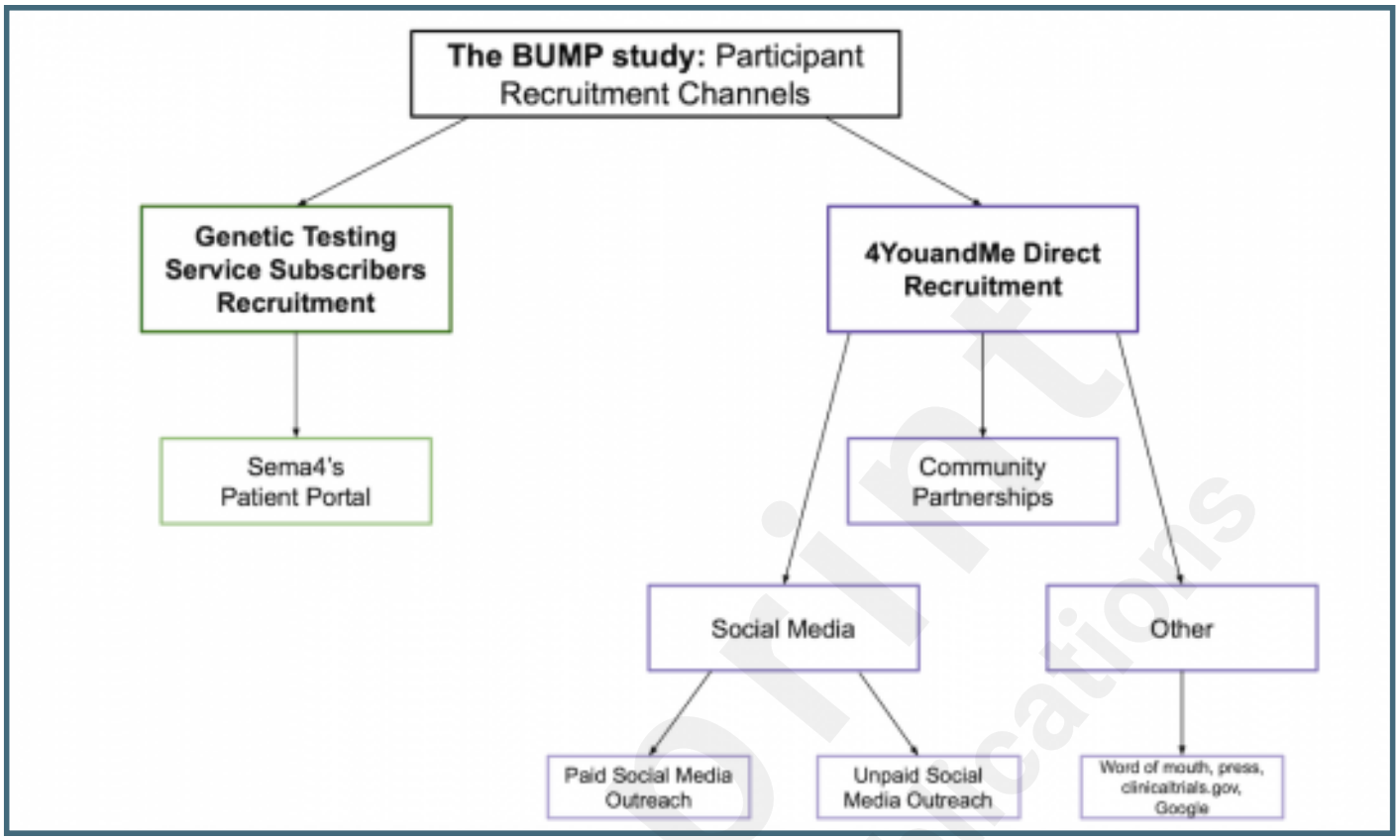
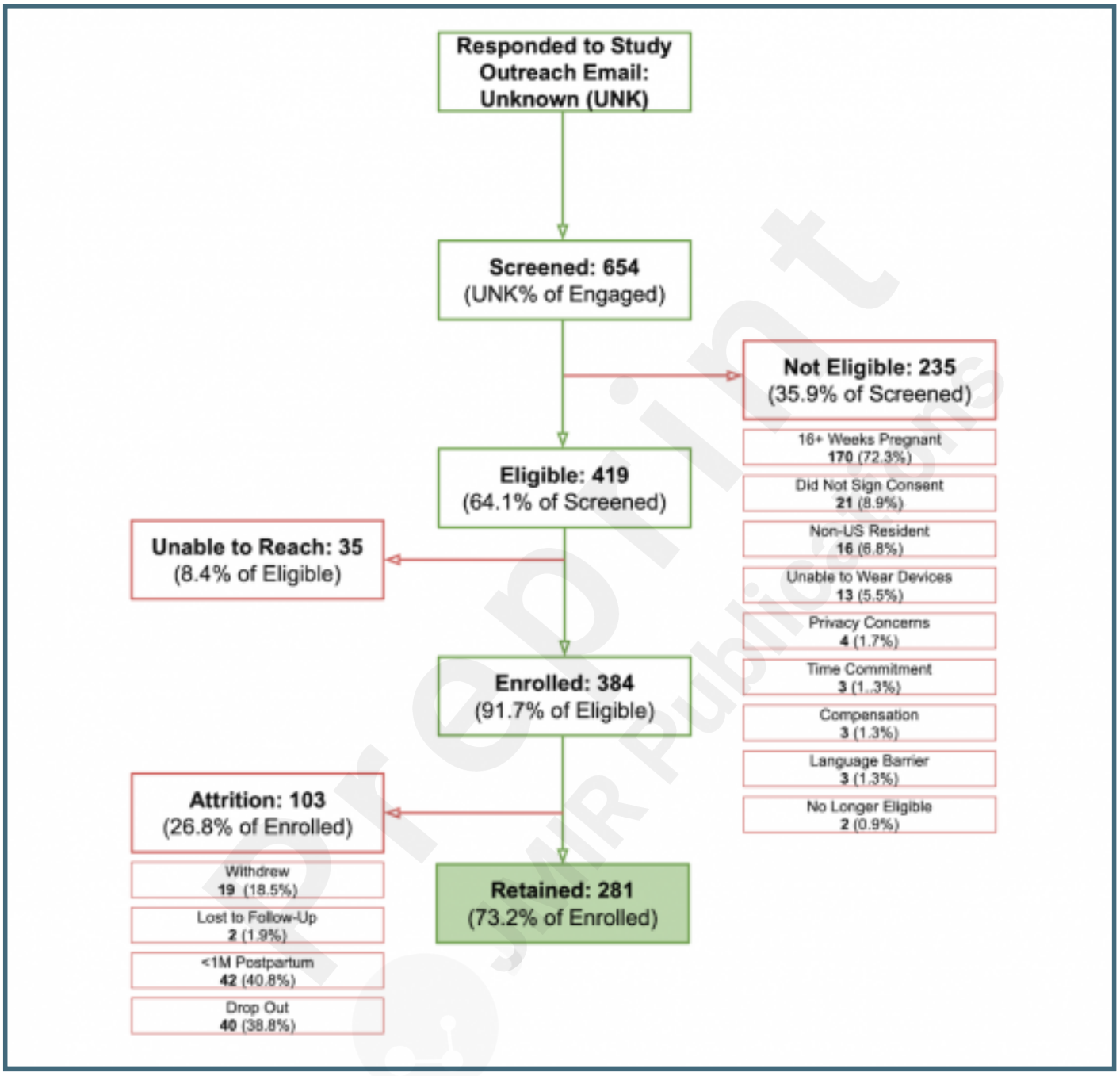
Supplementary Files

Figures

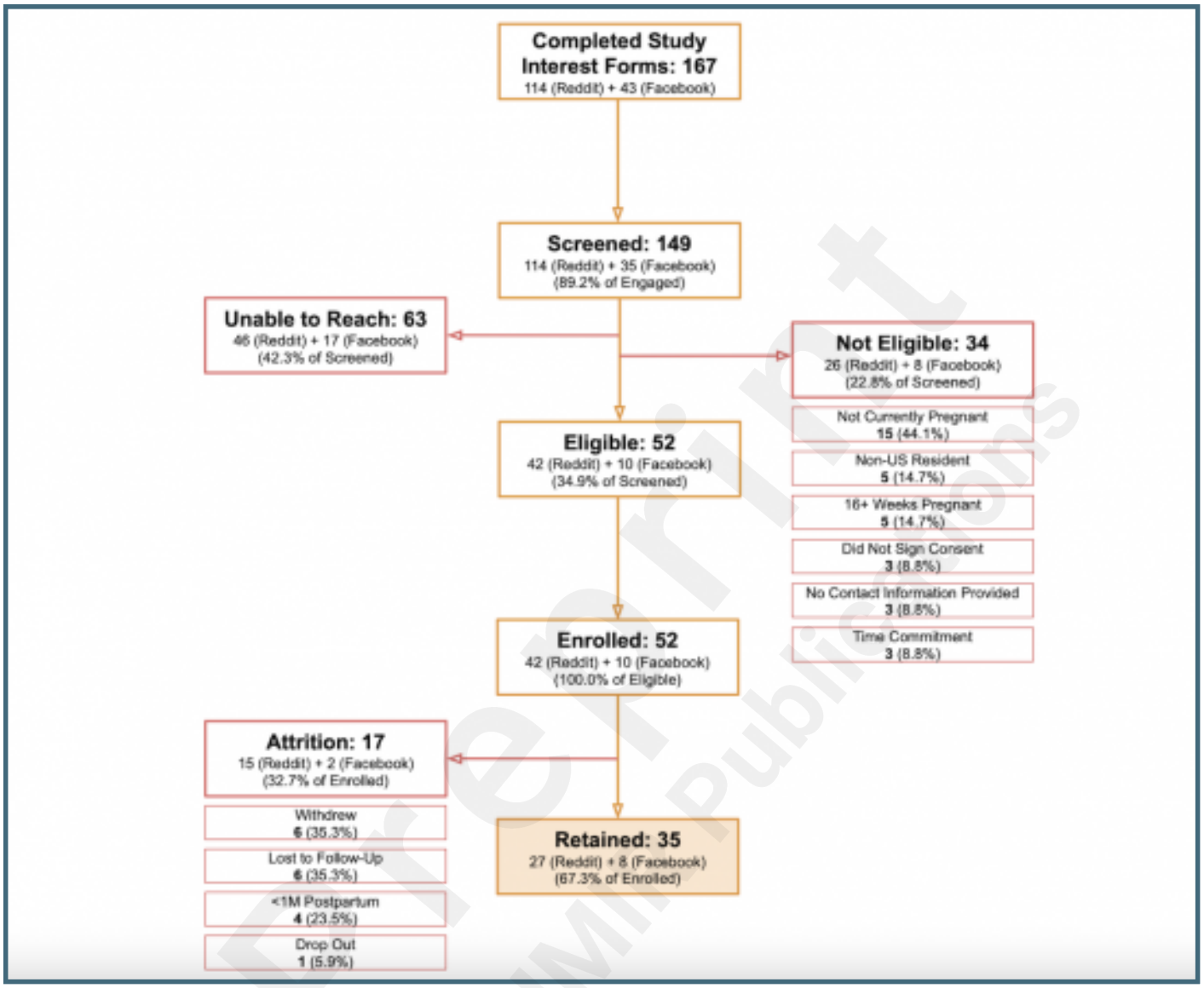
Flowchart of recruitment channels for The BUMP study.



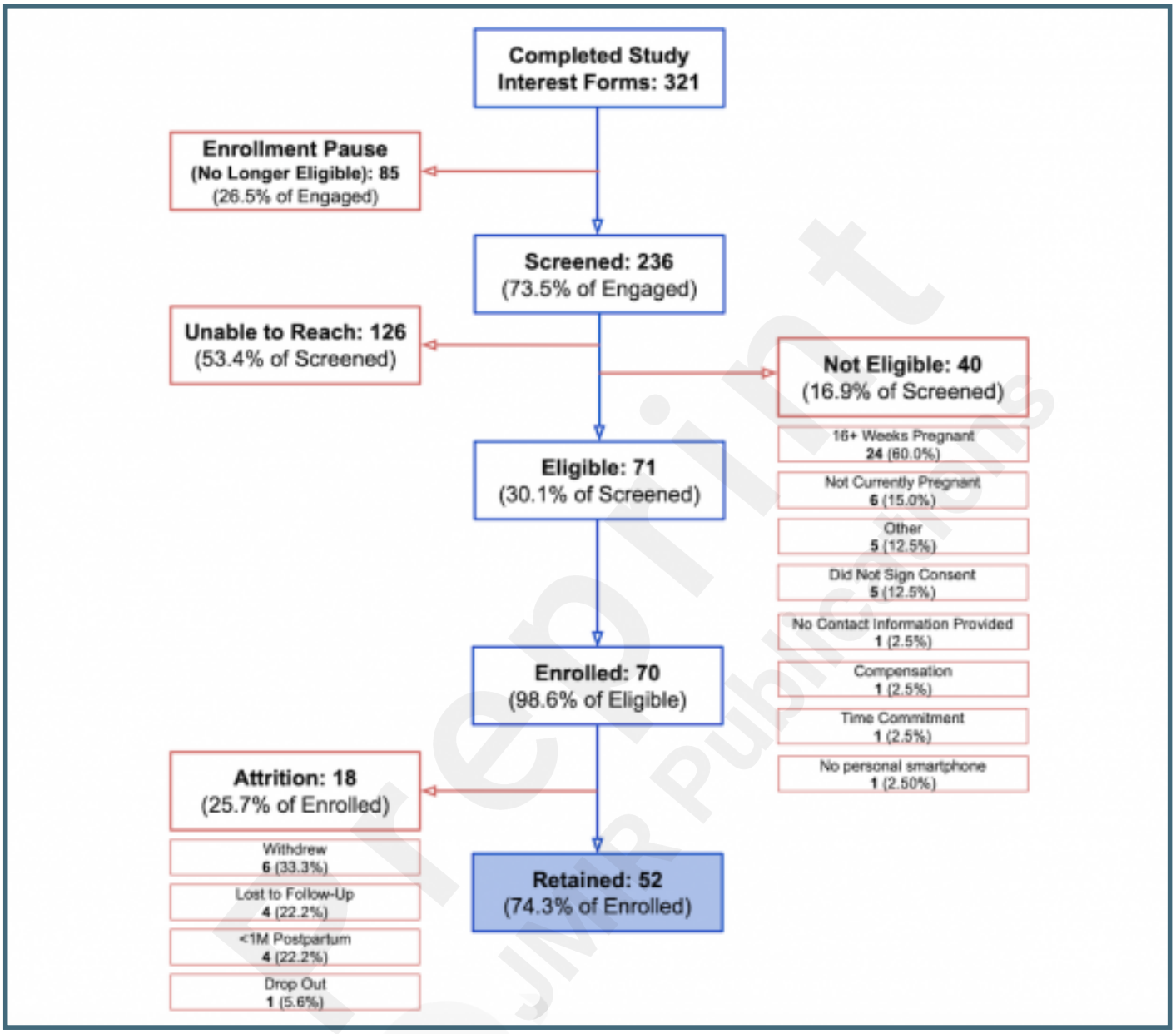
Engagement, enrollment and retention for the BUMP study from outreach via genetic testing service subscribers (Sema4).



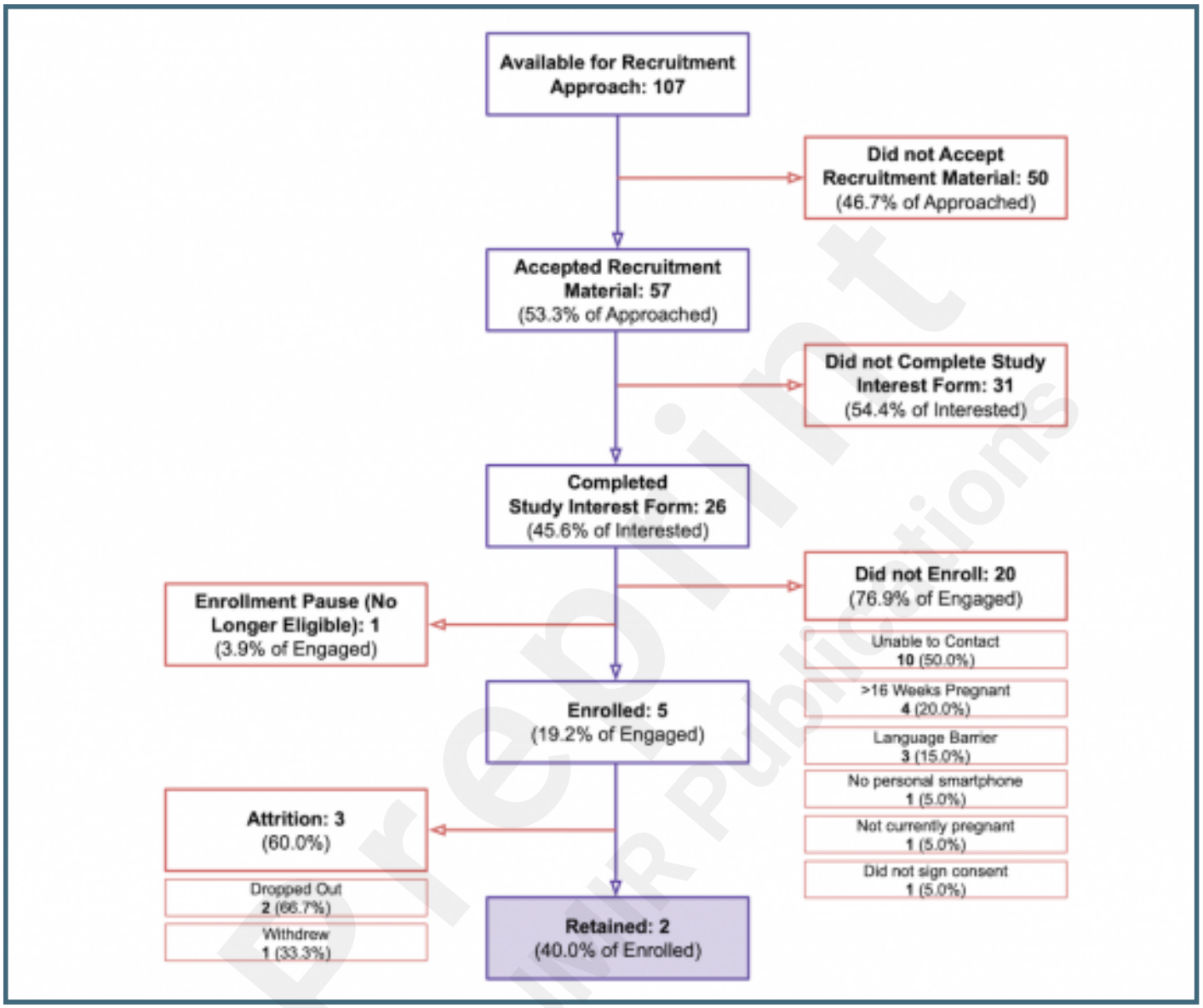
Engagement, enrollment and retention for the BUMP study from outreach via unpaid social media recruitment (Reddit and Facebook).



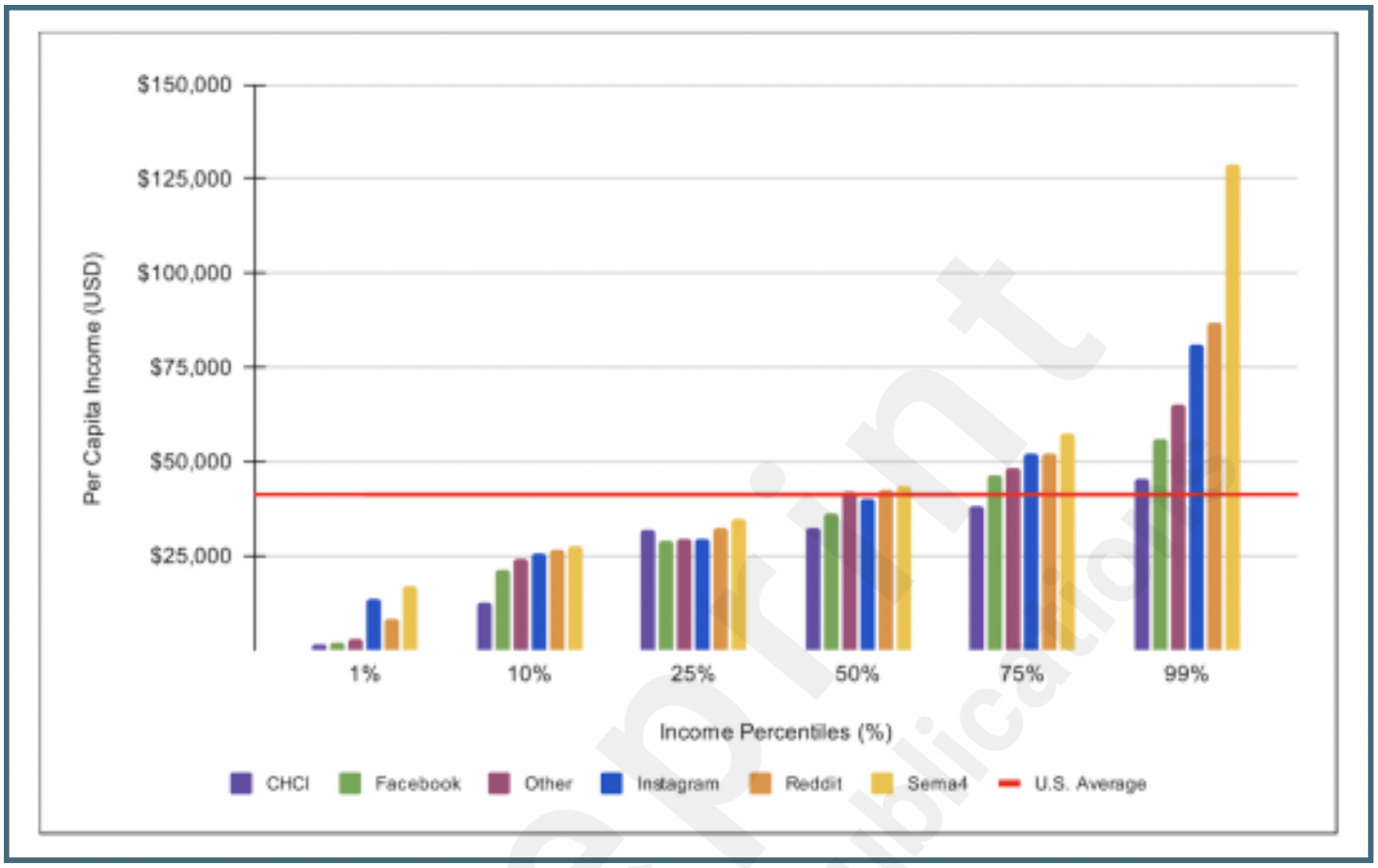
Engagement, enrollment and retention for the BUMP study from outreach via paid social media recruitment (Instagram).



Engagement, enrollment and retention for the BUMP study from outreach via Moses/Weitzman Health System.



Distribution of income per capita (USD) by zip code of enrolled participants in the BUMP study by recruitment method. (N=384, N=140 respectively).



Multimedia Appendixes

The BUMP Study Recruitment Flier for outreach via 4YouandMe direct recruitment approaches designed for long-form social media sites (e.g. Reddit).
URL: http://asset.jmir.pub/assets/a5d3d6506c8dd2e902a0c282f04cd52a.png

The BUMP Study Recruitment Flier for outreach via 4YouandMe direct recruitment approaches designed for long-form social media sites, designed for long-form social media sites (e.g. Reddit).
URL: http://asset.jmir.pub/assets/680f168a53807e4e37915208ec3df574.png

The BUMP Study Recruitment Flier for outreach via 4YouandMe direct recruitment approaches designed for long-form social media sites, text version. Designed for long-form social media sites with specific forums that did not allow images (e.g. Reddit).
URL: http://asset.jmir.pub/assets/ab33722b618de7b6727fe5464ef49d40.png

The BUMP Study Recruitment Flier for outreach via 4YouandMe direct recruitment approaches designed for long-form social media sites, tailored for image-dominant social media sites (e.g. Instagram).
URL: http://asset.jmir.pub/assets/1698faa4d544e736f1c3f77f0ac39c4e.png

The BUMP Study Recruitment Flier for outreach via 4YouandMe direct recruitment approach, tailored to community health partnerships (Moses/Weitzman Health System).
URL: http://asset.jmir.pub/assets/fec72a21af85a5a3ec033dd6c0e33fcf.png

The BUMP Study Recruitment Flier for outreach via 4YouandMe direct recruitment approach, (Moses/Weitzman Health System), alternate flier.
URL: http://asset.jmir.pub/assets/d680054041f2e6b5de1602c87d3e6438.png

Characteristics of the cohort among those who engaged (ENG) with recruitment materials, enrolled (ENR), and were retained (RTD) in the BUMP study for participants recruited via other methods.
URL: http://asset.jmir.pub/assets/443f1500a65d95b778237f3cdcadd433.png