Demographic and Socioeconomic Characteristics of Females in the Community Voices in Research Registry

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INTRODUCTION

Females, assigned at birth, with inheritable bleeding disorders (BDs) have historically been underrepresented in research. Community Voices in Research (CVR), a community-powered registry supported by the National Bleeding Disorders Foundation, collects the lived experience of people affected by bleeding disorders, including females.

AIM

This analysis aims to describe **female Community Voices in Research participants across a variety of social metrics.**

METHODS

- CVR collects self-reported information through voluntary electronic surveys. Adult individuals living with BDs and their immediate family members are eligible to participate.
- A retrospective analysis of a female sample, including data collected until July 1, 2025, will examine access to healthcare, time to diagnosis, pain, and reproductive tract bleeding symptoms (using the RUTA Aberdeen Menorrhagia Severity Scale).
- This abstract describes the sample by diagnosis, race, ethnicity, income, education, and employment.

REFERENCES

Santaella, M.E., Nichols, C.D. & Witkop, M. (2025). Community Voices in Research (CVR): A lived experience expert-centred approach to advance the future of inheritable bleeding disorders. The Journal of Haemophilia Practice, 11: 1, 136-146. https://doi.org/10.2478/jhp-2024-0020

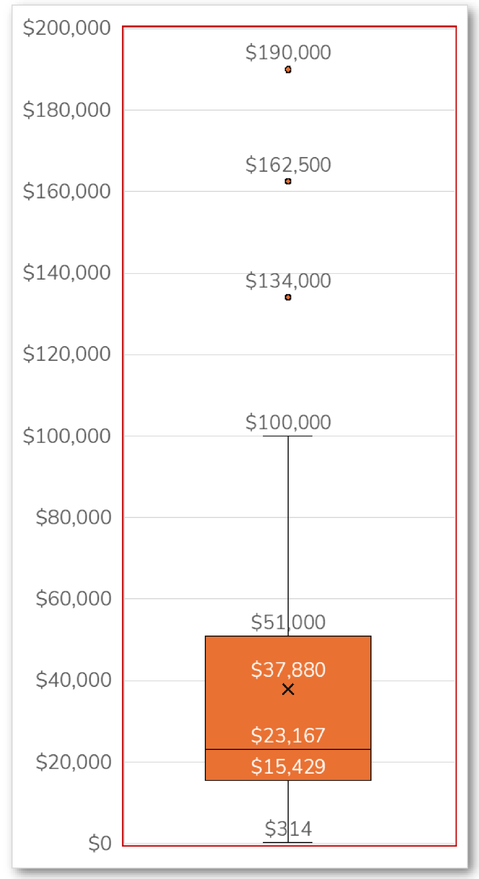
Table 1. *Female sample characteristics by diagnosis, race, ethnicity, education, and employment (N=398).*

Ethnicity	n	%
Not-Hispanic	332	83.42
Hispanic	61	15.33
Unknown	5	1.26
Race*	n	%
White	338	84.92
Black	37	9.30
Unknown	16	4.02
American Indian/Alaska Native	15	3.77
Asian	11	2.76
Middle Eastern/North African	3	0.75
South Asian	2	0.50
Native Hawaiian/Pacific Islander	1	0.25
Diagnosis	n	%
von Willebrand Disease	105	26.38
Hemophilia A	94	23.62
Ultra-Rare Disorders	55	13.82
Platelet Disorders	30	7.54
Hemophilia B	29	7.29
Another diagnosis	15	3.77
Unknown/Undiagnosed/Prefer not to answer	70	17.59
Education	n	%
Did not finish high school	3	0.75
High school diploma or GED	56	14.07
Some college but no degree	26	6.53
Trade school certificate	23	5.78
Associate's degree	16	4.02
Bachelor's degree	32	8.04
Master's degree	26	6.53
Doctorate or professional degree (PhD, JD, MD, etc.)	6	1.51
Unknown/Prefer not to answer	210	52.76
Employment Status	n	%
Full-time	165	41.46
Part-Time	57	14.32
Unemployed	55	13.82
Disabled	26	6.53
Prefer not to answer	95	23.87
*multiple responses allowed		

RESULTS

- Sample included 534 females (47.21% of total participants) – see *Table 1* for sample details.
- Of the 398 who completed the baseline survey:
  - The **majority are non-Hispanic** (n=332, 83.42%)
  - 65 (16.33%) reported a race other than White alone (including multiracial)
  - The mean age is **44.39 years** (range 19.64-80.89, SD 12.01).
- Of those with BDs (n=328), **VWD is the most common** (n=105), 32.01% of the total sample.
- Among those who reported education (n=188), the **most frequently reported highest level was a high school diploma/GED** (n=56, 29.79%).
- Of those who provided employment information (n=303), **most work full-time** (n=165, 54.46%).
- The median income of those who provided financial information (n=88) is $23,166.67 (range=$314.33-$190,000, IQR=$34,476.19), see *Figure 1*.

Figure 1. *Income adjusted for number of persons living in household (N=88).*



CONCLUSIONS

- CVR captures the experience of living with a BD directly from those affected by them, providing valuable insight.
- This sample is diverse in age and diagnosis, although the ultra-rare disorders are underrepresented. Socioeconomic data suggest some variability; but while the vast majority have at least a high school diploma or equivalent and most work full-time, females reported modest incomes with a wide range.
- Future analyses will evaluate the relationship between these variables and access to care.

PLAIN LANGUAGE SUMMARY

The Community Voices in Research registry is powered by the community and collects information about what it is like to live with a bleeding disorder from the people who know these conditions best: those with lived experience. This study describes a sample of female participants based on their diagnosis, race, ethnicity, income, age, employment, and education. Most participants identify as non-Hispanic and White. About half of the sample has a diagnosis of von Willebrand disease (VWD) or hemophilia A. The average age of participants is approximately 44 years. Most work full time, and the most commonly reported level of education is a high school diploma or equivalent. After adjusting for household size, the median annual income is about $23,000, with incomes ranging from $314 to $190,000. Researchers are continuing to study this sample to better understand how these demographic and socioeconomic factors relate to reproductive bleeding experiences among females. AI was used for this summary.