Underserved People in the Prader-Willi Community

Host Organization: Colors of Hope with facilitators from I AM ALS

Sponsors: Soleno Therapeutics and Acadia Pharmaceuticals

Report prepared by Dini Rao, Co-Organizer of Colors of Hope
with Co-Organizers Charles and Gennelle Conway, Karine Kabundi and Sarah Kasaby

Feb, 2026

Contents:

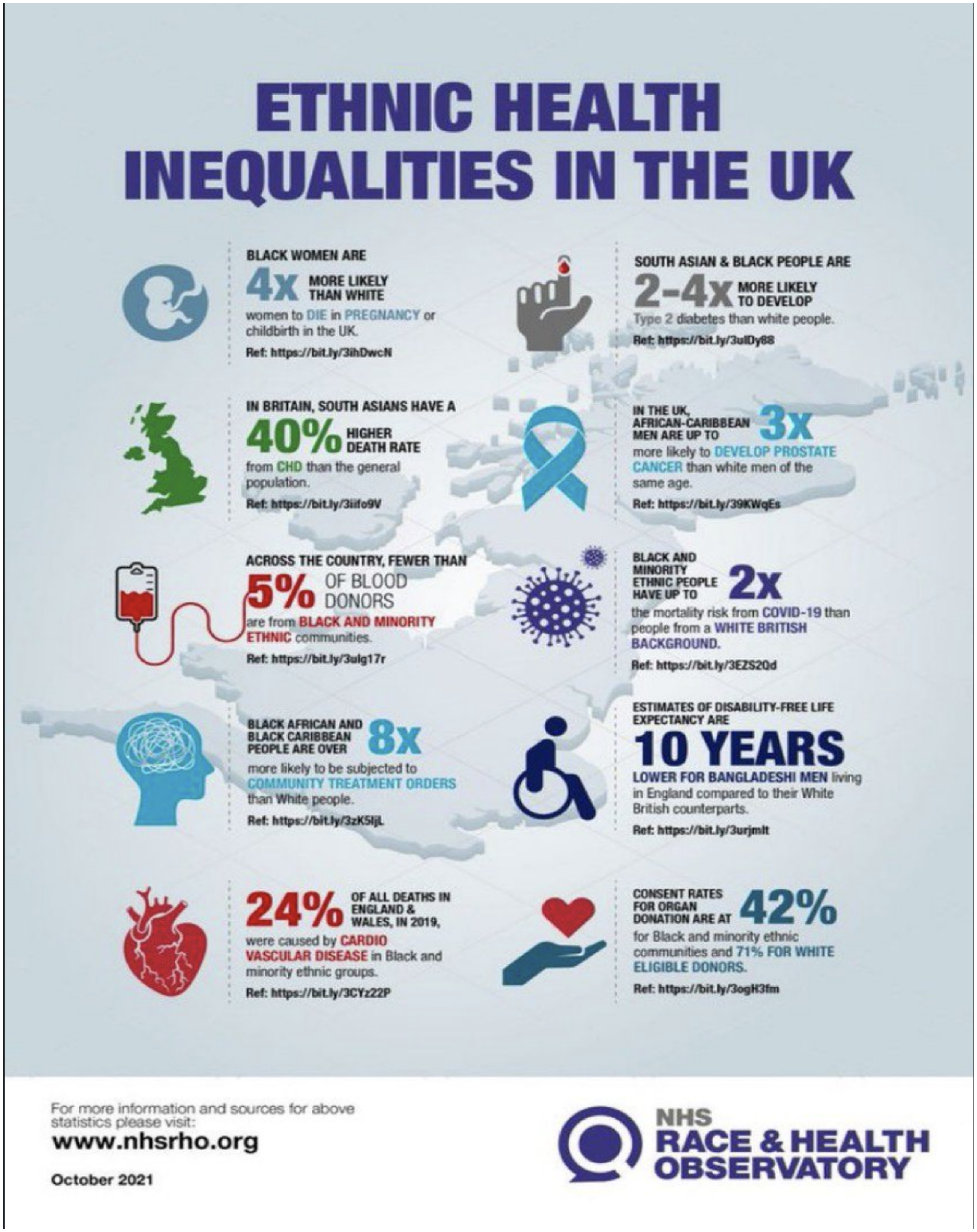
Executive Summary

Prader-Willi Syndrome (PWS) is a rare genetic disorder requiring lifelong management. Organizations such as Prader-Willi Syndrome USA, (PWSA|USA), the Foundation for Prader-Willi Research (FPWR), PWS clinics and specialists provide ties and support leading to interventions that improve quality of life and health outcomes for persons living with PWS. When entire communities are undiagnosed, missing or not served, lifespans are lower and quality of life is worse. The Black, Indigenous and People of Color (BIPOC) community is one such group. While caregiving and care is demanding across all populations, BIPOC caregivers/advocates often face additional layers of challenges compounded by systemic racism, cultural stigma, and lack of representation in rare disease spaces.

Listening sessions were convened to elevate the voices of BIPOC caregivers, identify gaps in care and representation, and generate recommendations for future action for healthcare providers, advocacy groups, and policymakers. It is a first step towards establishing foundational alignment on what the experiences of the BIPOC community are, so progress can be measured and made.

Despite the small sample sizes, these listening sessions and surveys with BIPOC caregivers of individuals with Prader-Willi Syndrome (PWS) revealed deep insights into the unique challenges faced by these families. While participants were largely well-resourced, they highlighted systemic inequities, cultural barriers, and unmet needs for connection, support, and representation. They highlighted a strong desire for cultural connection, family education, and equitable access to care, while also recognizing the importance of allies in advancing change. Ultimately the data points to action needed for better diagnosis, treatment and outcomes for people of color.

In the rare disease community, we know all too well what it feels like not to be seen, not to have our needs recognized and met. Community leaders and decision makers need to work to make sure we aren’t perpetuating this cycle by allowing the BIPOC community to suffer unnecessarily. Without direct action, health and educational inequities will resort to the common outcomes we see worldwide for the BIPOC community such as seen in this chart:



ETHNIC HEALTH INEQUALITIES IN THE UK

BLACK WOMEN ARE **4x** MORE LIKELY THAN WHITE women to **DIE** in **PREGNANCY** or childbirth in the UK.

Ref: https://bit.ly/3ihDwcN

IN BRITAIN, SOUTH ASIANS HAVE A **40%** HIGHER DEATH RATE from **CHD** than the general population.

Ref: https://bit.ly/3iifo9V

ACROSS THE COUNTRY, FEWER THAN **5%** OF BLOOD DONORS are from **BLACK AND MINORITY ETHNIC** communities.

Ref: https://bit.ly/3ulg17r

BLACK AFRICAN AND BLACK CARIBBEAN PEOPLE ARE OVER **8x** more likely to be subjected to **COMMUNITY TREATMENT ORDERS** than White people.

Ref: https://bit.ly/3zK5IjL

24% OF ALL DEATHS IN ENGLAND & WALES, IN 2019, were caused by **CARDIO VASCULAR DISEASE** in Black and minority ethnic groups.

Ref: https://bit.ly/3CYz22P

SOUTH ASIAN & BLACK PEOPLE ARE **2-4x** MORE LIKELY TO DEVELOP Type 2 diabetes than white people.

Ref: https://bit.ly/3ulDy88

IN THE UK, AFRICAN-CARIBBEAN MEN ARE UP TO **3x** more likely to **DEVELOP PROSTATE CANCER** than white men of the same age.

Ref: https://bit.ly/39KWqEs

BLACK AND MINORITY ETHNIC PEOPLE HAVE UP TO **2x** the mortality risk from **COVID-19** than people from a **WHITE BRITISH BACKGROUND.**

Ref: https://bit.ly/3EZS2Qd

ESTIMATES OF DISABILITY-FREE LIFE EXPECTANCY ARE **10 YEARS** **LOWER FOR BANGLADESHI MEN** living in England compared to their White British counterparts.

Ref: https://bit.ly/3urjmlt

CONSENT RATES FOR ORGAN DONATION ARE AT **42%** for Black and minority ethnic communities and **71% FOR WHITE ELIGIBLE DONORS.**

Ref: https://bit.ly/3ogH3fm

For more information and sources for above statistics please visit:

www.nhsrho.org

October 2021

NHS
RACE & HEALTH
OBSERVATORY

When you recognize that “race” is not a biological concept but **rather a social construct**, it becomes clear that these variances in outcomes have social drivers. Social drivers such as Economic Stability (income, job security), Education Access (Special Education services, vocational training), Healthcare Access, your Neighborhood (housing, healthy food, safety, pollution), and Social & Community Context (discrimination, social support) play a major role for the Prader Willi Community. There is nothing uniquely challenging with diagnosing people of color in terms of genetic blood testing or methylation analysis, instead they are less likely to have access to testing for various reasons discussed in this report.

In a report by the Rare Disease Diversity Coalition (RDDC), they note, “Marginalized groups are **disproportionately** affected by health disparities, resulting in longer diagnostic delays and poorer health outcomes. Investigating the extent of these disparities— particularly within specific subpopulations—and addressing health equity in rare disease care (including ultra-rare conditions like PNH - Paroxysmal nocturnal hemoglobinuria) is crucial for developing targeted interventions and improving outcomes for rare disease patients.”[1]

Data shows us that health, educational and quality of life inequities exist by race and ethnicity around the globe. So, the question we are faced with is not whether they exist in the PWS community, but how? To move this work forward, we recommend targeted and culturally sensitive approaches to improve results, rather than a color-blind, one-size-fits all approach that has been used to date.

Everyone will reap the benefits of this work. A focus on BIPOC communities will pay dividends to the entire community. If you focus on outcomes for the most marginalized populations, you will help everyone, including the “white population" (people of European descent).

Key Themes explored in this report:

- 1. People & Research - people of color are missing across the board from rare disease events, databases, and clinical trials.
    - **Representation and outreach** to BIPOC communities is low. For BIPOC populations compared to white populations:
        - Data for BIPOC folks is **extremely low** in the global registry.
        - **Diagnosis** for BIPOC occurs later or perhaps not at all.
        - Presence of BIPOC at conferences, events and foundation databases is low and **under-represented** as a result of low outreach efforts.
        - The representation of BIPOC in **clinical trials** is low.
        - **Trust** is not there for historical reasons.
- 2. Community Connections
    - **Families need education, both within nuclear and extended units** with culturally relevant resources.
    - **Safe spaces** are needed for sharing, grieving, and celebrating milestones.

---

[1] “Healthy Equity for People Living with PNH: Creating a Leveled Playing Field” Rare Disease Diversity Coalition https://www.rarediseasediversity.org/hubfs/RDDC/health-equity-pnh.pdf?hsLang=en

    - **Food and culture** are central to community wellbeing but create stress and exclusion.
    - Lack of **bandwidth** amongst BIPOC **caregivers** also leads to lower participation rates and higher isolation/stress levels.
- 3. Healthcare Systems:
    - **Lack of representation** amongst healthcare authorities (doctors especially)
    - Families of color often feel **dismissed or disrespected by healthcare professionals** despite strong advocacy.
    - **Comorbidities** also go undiagnosed at a greater rate for BIPOC.
    - Provider **bias** can lead to inconsistencies in treatment
    - **Access** to appropriate care is critical for all communities.
- 4. Policy/Programs
    - **Peer support and mentorship** are vital but effective only if well-trained and culturally attuned.
    - **Program cuts** for Medicaid, Special Education, etc will affect more vulnerable populations more intensely.
    - **Policy supports** are needed to promote rare disease research/cures much the same way they are needed to ensure BIPOC representation.

Each of these themes presents challenges and needs and based upon those, we've given some recommendations.

More About Colors of Hope

Colors of Hope is an affinity group for BIPOC families affected by Prader Willi Syndrome. Our mission is to empower, connect and support caregivers and individuals with Prader-Willi Syndrome who are Black, Indigenous and People of Color through community-driven research, education, and advocacy. By uniting and uplifting diverse voices and experiences, we aim to improve health outcomes and the overall quality of life for all.

We envision a future where our loved ones regardless of their skin color, their financial status or/and their background live limitless lives. We aim to build understanding and empathy for people living with PWS by creating supportive and inclusive communities. We see a future where people of all shades are able to live their best healthy lives.

www.pwscolorsofhope.org/

Methodology for the Listening Sessions

- **Format:**
    - Facilitated listening sessions (virtual) by I AM ALS professionals Aditi Minkoff and Michael Lecker and hosted by Colors of Hope Organizers.
    - Followed by survey sent to Colors of Hope group
    - 12pm ET March 4 - 2 participants (PWS kids ages 3 and 5)
    - 6:30pm ET March 13 - 6 participants (PWS ages 8 months, 3, 4, 8, 15, 17) 12pm ET March 20 2 participants (PWS ages 5 and 30s)
    - 6:30pm ET March 25 3 participants (PWS 8, 20s and 30s)
- **Participants:** BIPOC caregivers of children with PWS.
    - 12 interviewees in Listening Sessions
    - 20 survey respondents (13 who did not attend a Listening Session)
        - Those who completed the survey but did not attend cited “not enough time” as the main reason for not participating in a Listening Session.
    - Ages of loved ones with PWS: infant to 33yrs old
- **Focus:** Experiences with diagnosis, family support, healthcare access, and community needs, strengths and values.
- **Limitations:** This data represents a small sample size that primarily represents well-resourced families. For this reason, we’ve taken data from other population sets that are comparable as well. We recommend doing **a broader validation study** because we are hearing these themes consistently and frequently, so we know this is just the starting point. Racial/ethnic inequities are systemic worldwide, so we need to figure out how this is showing up in our community.

Participant Demographics

- Caregivers of children diagnosed with PWS, mostly early in life.
- Majority connected to support networks or healthcare systems.
- Of the 12 interviewees from 12 states:
    - 5 Black
    - 3 East Asian
    - 2 South Asian
    - 2 Middle Eastern
    - PWS Loved ones ages: 8 months-30’s yrs old
    - 3 males, 9 females - 4 with sons, 8 with daughters
- **Missing:** People living with PWS, Latine & Indigenous families, LGBTQIA+ families, families without insurance, without connections to Colors of Hope, those facing stigma around genetic testing or overall missing diagnosis.

Theme 1: People & Research

Where are the people of color?

As Ashish Rishi, Health Equity Strategist says: “If your data excludes people, your service does too. It really is that simple.”

Challenge: Missing Data

To date, there is no known research about the people of color living with Prader Willi Syndrome - their described features, their numbers, their subtypes. It has been stated that the occurrence rate of PWS is equal amongst all genders, races and ethnicities, however the presence of BIPOC living with PWS is not representative in any database.

What we know:

- **There are many folks living with PWS who are unaccounted for.** Currently, the PWSA USA database lists about 12,000 people living in the USA with PWS. Looking at 2024 population data and a PWS occurrence rate of 1:20,000 births the number of people in the US diagnosed with PWS should be closer to 20,000. This leaves a gap of 8,000+ people in the US who may not be receiving services or specialty PWS care.[2] Beyond this number, there may also be a significant undiagnosed population that the occurrence rate does not consider. (The occurrence rate is calculated as a result of new diagnoses divided by the population.)
- **People of Color are missing from the PWS Global Registry.**
    - PWS Global Registry Data has 1311 participants. Of those respondents, those who identify as Asian, Black, American Indian or Native Alaskan, Native Hawaiian or Pacific Islander are only 6.4% of the registry *compared to 25%* in the 2022 US Census.
    - Similarly there are only 9.5% Hispanic/Latine respondents *versus 19%* in the 2022 US Census[3].
- Representation in CLIC databases where healthcare providers are collecting information is better, but there is limited data collected there and CLIC sites are geographically limited at the moment.

➡️ **Needs:** Representational data to set a baseline, prioritize needs and measure progress.

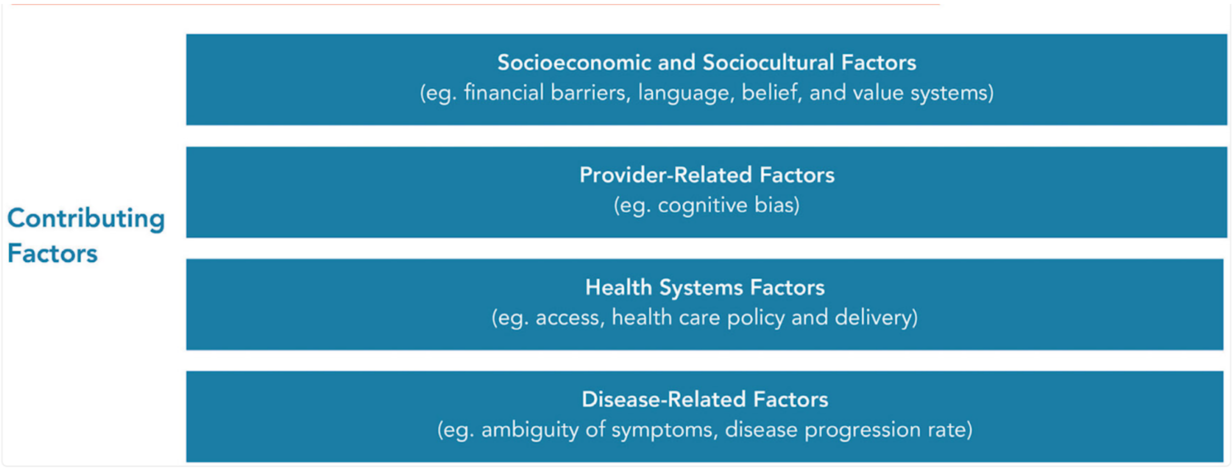
Challenge: Lower and Slower Diagnosis Rates

- Part of the picture for missing people of color and data is that diagnosis delays are problematic. We see this across many disease and rare disease populations.

---

[2] PWSA USA CEO Stacy Ward confirms this number as of Jan 5, 2026 from PWSA USA records.
[3] Prader Willi Syndrome Global Registry Data as of Sept 2024 https://pwsregistry.org/

- “Globally, published studies have consistently shown that underserved racial and ethnic populations are more likely to experience a diagnostic delay in a range of clinical conditions,”[4] according to a research paper titled “Experiences with diagnostic delay among underserved racial and ethnic patients: a systematic review of the qualitative literature,” which explores patient experiences and causes of these delays. The authors break down the contributing factors into these categories:



- We see this delay in Prader-Willi Syndrome, as the diagnosis pathways have not been established for all racial and ethnic populations. A paper on the “Age of Diagnosis for children with chromosome 15q syndromes” in the *Journal of Neurodevelopmental Disorders* in 2023 stated, “We do not know how many individuals remain undiagnosed or misdiagnosed, nor do we have a full appreciation for how the diagnostic process may differ for individuals from different race, ethnic, or socioeconomic backgrounds. For example, PWS deletions are often associated with decreased OCA2 gene expression, leading to a “blonde hair, blue-eyed” phenotype, even in families with typically darker features. This may result in underdiagnoses among African and Hispanic Americans who do not “look” like the children with PWS presented in most textbooks.”[5]
- These statistics match the life experiences of those in our group. Participants in our Listening Sessions shared stories about not being believed, facing rude, inattentive or under-educated providers, alongside the implicit bias of physicians believing that our populations have poor diets or are less critical to care for.

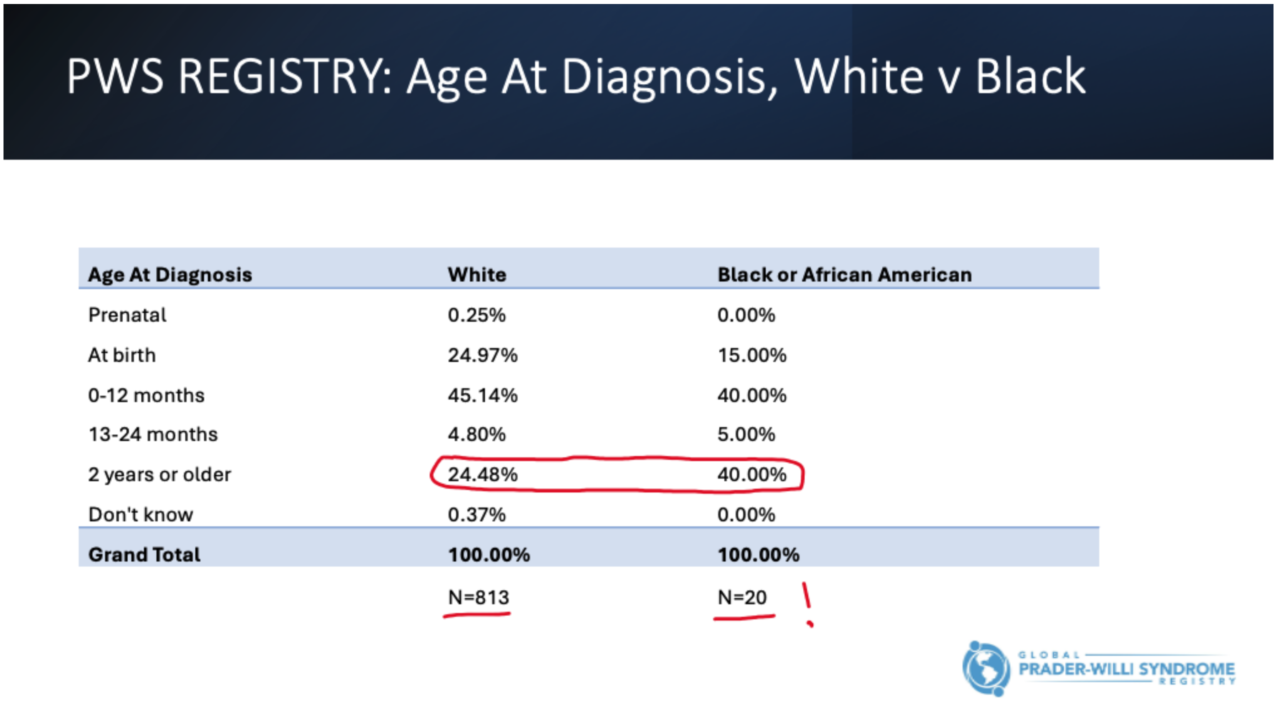
---

[4] Elena Faugno, Alison A Galbraith, Kathleen Walsh, Paul J Maglione, Jocelyn R Farmer, Mei-Sing Ong. “Experiences with diagnostic delay among underserved racial and ethnic patients: a systematic review of the qualitative literature” *BMJ Quality & Safety.* Mar 1, 2025 https://pubmed.ncbi.nlm.nih.gov/39496473/

[5] Wheeler, Anne C., Gantz, Marie, Cope, Heidi, Strong, Theresa V, Bohonowych, Jessica E, Moore, Amanda, and Vogel-Farle, Vanessa. “Age of diagnosis for children with chromosome 15q syndromes” *Journal of Neurodevelopmental Disorders,* 2023. https://link.springer.com/content/pdf/10.1186/s11689-023-09504-x.pdf

- An Institute of Medicine report on disparities in healthcare found: **“Physicians sometimes had a harder time making accurate diagnoses because they seemed to be worse at reading the signals from minority patients, perhaps because of cultural or language barriers.** Then there were beliefs that physicians already held about the behavior of minorities. You could call these stereotypes, like believing that minority patients wouldn’t comply with recommended changes.”[6]

When looking to answer the question, do Black people have a later diagnosis than white people for PWS, the population size in the PWS Global Registry is only 20 respondents compared to 813 white ones. Even this small amount of data suggests diagnosis does come later, as is confirmed by other rare disease data.



PWS REGISTRY: Age At Diagnosis, White v Black

Age At Diagnosis	White	Black or African American
Prenatal	0.25%	0.00%
At birth	24.97%	15.00%
0-12 months	45.14%	40.00%
13-24 months	4.80%	5.00%
2 years or older	24.48%	40.00%
Don't know	0.37%	0.00%
Grand Total	**100.00%**	**100.00%**
	N=813	N=20 !

Implications:

These delayed diagnoses have a huge impact on an already under-resourced population: According to Global Genes, “**The economic impact of a delayed diagnosis can reach up to $517,000 in avoidable costs per patient**.”[7] This statistic is not specific to PWS, where the figure could easily be higher.

➡️ **Needs:** More effective diagnosis pathways for BIPOC people living with PWS.

---

[6] Carroll, Aaron E. “Doctors and Racial Bias: Still a Long Way to Go”, *New York Times*, Section A, Page 14 Feb 25, 2019. https://www.nytimes.com/2019/02/25/upshot/doctors-and-racial-bias-still-a-long-way-to-go.html

[7] https://globalgenes.org/rare-disease-facts/

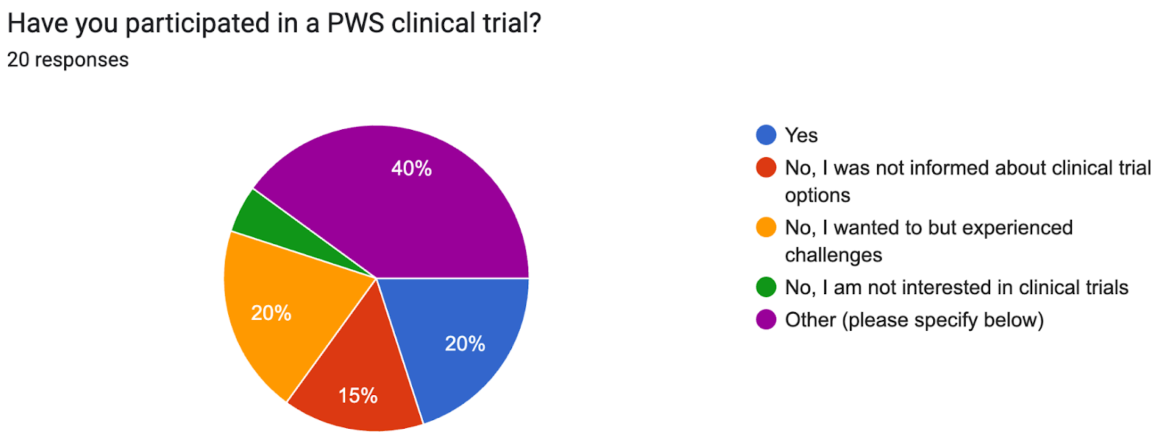
Challenge: Missing from Clinical Trials:

Without proper diagnosis rates, it is not surprising that BIPOC are also missing from clinical trials. In a recent Prader Willi Phase 3 trial, 84.7% of trials participants were white for Phase 3, according to the NIH PubMed reports[8] and that is not unusual.

According to a 2024 report from the Department of Health and Human Services, “People from non-White, non-Hispanic racial and ethnic backgrounds tend to be underrepresented in the rare disease clinical trials we examined relative to the incidence rates for these groups.”[9]

As professors Andrew E P Mitchell and Sondra Butterworth state in their article, *Enhancing Equality, Equity, Diversity and Inclusion in Rare Disease Research in the United Kingdom*: “The **absence risks research relevance** and its potential impact on research practice.” and that “Improving research inclusion requires trust, research literacy, partnership, and working together in setting the agenda for research.”[10]

When we asked those surveyed about PWS clinical trials, they responded that only 20% of this relatively well-informed and resourced group had participated.


Have you participated in a PWS clinical trial?

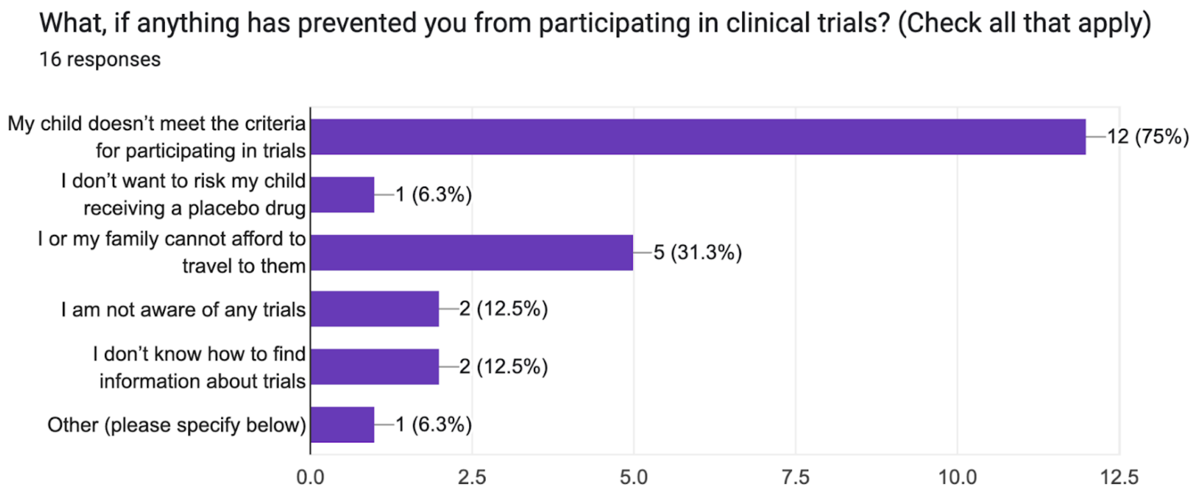
20 responses

---

[8] Miller, Jennifer L. et al. “Diazoxide Choline Extended-Release Tablet in People With Prader-Willi Syndrome: A Double-Blind, Placebo-Controlled Trial.” *Journal of Clinical Endocrinology and Metabolism*. Volume 108, Issue 7, July 2023, Pages 1676–1685, Jan 14, 2023. https://pmc.ncbi.nlm.nih.gov/articles/PMC10271219/

[9] “Participant Diversity by Race, Ethnicity, and Sex in Rare Disease Clinical Trials: A Case Study of Eight Rare Cancers” Oct 16, 2024 https://aspe.hhs.gov/reports/cancer-trial-diversity?utm_source=chatgpt.com

[10] Mitchell, Andrew EP and Butterworth, Sondra. “Enhancing Equality, Equity, Diversity and Inclusion in Rare Disease Research in the United Kingdom” *Nurs. Rep. 15*(10), 361; Oct 9, 2025. https://doi.org/10.3390/nursrep15100361


What, if anything has prevented you from participating in clinical trials? (Check all that apply)
16 responses

Looking at our limited survey data, there is interest in participating in clinical trials generally amongst this group surveyed, but our community faced obstacles and a surprising number weren't aware of or knew how to find information about the trials (4 respondents). We believe this indicates a lack of connectivity that exists for many out there still and is probably much higher for those we haven't reached yet.

Other obstacles to participating in clinical trials mentioned:
Multiple stories of “they never got in touch with me.”
“Not sure of what it entails, tricky with how much insurance covers vs clinical trial. Also traveling costs?”
“I would like to be notified of any clinical trials. I also don't feel that all information/options are advised to me by physicians.”
“Cost of travel.”
“Was not accepted to the clinical trial we were trying for.”

➡️ **Needs:** Systematic reporting of race/ethnicity in all PWS trials, targeted outreach and diversity targets, education and relationship/trust building early on in clinical trials as well as inclusion in study design. The earlier the outreach, the better.

Challenge: Missing Participation/Outreach

Not only are people of color with PWS missing from research, they are also missing from the community at large.

- Small numbers of people of color present in the PWSA USA & FPWR databases, conferences and events suggest a large number of families who are not yet connected or diagnosed.
- For the most part, demographic data has not been collected, so we don't even know the extent of the problem.

- While data was not collected previously on attendance at conferences, (which is data by itself) attendance at United in Hope 2025 was nearly 20% BIPOC as a result of targeted efforts made by Colors of Hope, FPWR, IPSWO and PWSA USA.
- However attendees noted that more work needed to be done:
  - When asked in our survey - “What would entice you/more BIPOC to attend conferences?”
    - BIPOC Topics (9 mentions)
      - More BIPOC medical professionals/speakers
      - BIPOC topics for the larger group including research/data
      - BIPOC issues and solutions/actions
    - Financial Considerations (7 mentions) (or perhaps more communication about scholarship opportunities)
      - Travel budget
      - Location close to home
    - Childcare (4 mentions)
    - Other mentions:
      - Adequate notification of conferences
      - More networking time
      - Alternate time/location - school holidays?
      - Didn’t know about the conference

➡️ **Needs:** Relevant speakers/topics, financial support, childcare, more outreach and remote options.

Challenge: Lack of Trust for Institutions

Historically many marginalized, non-white communities have reasons to mistrust medical establishments. To move forward, we have to address this past and work to overcome these obstacles.

- In the report on Diagnostic Delays mentioned above the researchers found that institutional distrust was a barrier to diagnosis. They wrote, *“Institutional distrust, stemming from historical traumas or prior experience of unequal treatment, was also a major deterrent for patients to engage with healthcare systems. Notably, among AIAN communities, childhood developmental screening and subsequent interventions were perceived as attempts to acculturate AIAN children, as one parent remarked ‘seeking help outside your family is a colonisation issue’. Some parents expressed concern that their children would be taken away from them if screening identified problems. Among some black patients, the belief that publicly insured and black patients were treated differently was also a deterrent to seeking medical care. Some black parents also expressed fear that a diagnosis of developmental disability would lead to further mistreatment or abuse of their children by healthcare systems.”*[11] While these comments

---

[11] Faugno, Elena, Galbraith, Alison A, Walsh, Kathleen, Maglione, Paul J, Farmer, Jocelyn R, and Ong, Mei-Sing. “Experiences with diagnostic delay among underserved racial and ethnic patients: a systematic

were not from the Prader-Willi community, these caregivers' voices can reveal insights into what we may not be able to see.

- Appropriate steps forward must include an understand of the historical context that has caused much of this distrust:
    - “Thousands of nonwhite women have been sterilized without consent.[12] For instance, between the 1930s and 1970s, one-third of Puerto Rican women of childbearing age were sterilized[13], many under coercion. Likewise, in the 1960s and 1970s, thousands of Native American women were sterilized without consent.[14]”
    - Biased care: “There’s significant literature documenting that African-American patients are treated differently than white patients when it comes to cardiovascular procedures. There were differences in whether they received optimal care with respect to a cancer diagnosis and treatment. African-Americans were less likely to receive appropriate care when they were infected with H.I.V. They were also more likely to die from these illnesses **even after adjusting for age, sex, insurance, education and the severity of the disease**.”[15]
- While our participants didn’t cite lack of trust as a reason for lack of participation, this may not represent the larger BIPOC population and intuitively this may be caused by a lack of trust in even this process where participants didn’t feel they could be fully transparent yet. There are many layers of fear and mistrust to work through when it comes to racial and ethnic bias.

➡️ **Needs:** Work slowly and transparently with the BIPOC community to provide value and build relationships. *Beware of attempts that require BIPOC to place trust and effort first, are culturally insensitive, overly transactional or feel like tokenization.*

Implications on Research

- As a result of the missing data, outcomes for the BIPOC community suffer - it is less known how disorders manifest or how they respond to treatments.
- Research as a whole suffers as a result of missing people in the data. As Dr. Gary A. Puckrein, CEO of the National Minority Quality Forum, said on the intersection of equity and data science at the Indo US Bridging Rare Summit 2025 : “***We cannot achieve precision medicine without inclusion; diversity is the engine of discovery.***”

---

review of the qualitative literature” *BMJ Quality & Safety.* Mar 1, 2025 https://pubmed.ncbi.nlm.nih.gov/39496473/

[12] Stern, Alexandra Minna. “That Time The United States Sterilized 60,000 Of Its Citizens”Huffington Post. Jan 7, 2016. https://www.huffpost.com/entry/sterilization-united-states_n_568f35f2e4b0c8beacf68713

[13] Louis de Malave. “Sterilization of Puerto Rican Women: A Selected, Partially Annotated Bibliography”1999

[14] “1976: Government admits unauthorized sterilization of Indian Women” Native Voices, Native Peoples’ Concept of Health and Illness

[15] Carroll, Aaron E. “Doctors and Racial Bias: Still a Long Way to Go”, *New York Times*, Section A, Page 14 Feb 25, 2019. https://www.nytimes.com/2019/02/25/upshot/doctors-and-racial-bias-still-a-long-way-to-go.html

People and Research Recommendations

- Conduct broader validation surveys with trusted BIPOC-focused organizations.
- Partner with specialist medical associations, clinics, state orgs, and community health workers. Who are trusted messengers?
    - If not culturally trained, also not useful
- Create new pathways for families of color to get diagnosed
    - Expand research to include BIPOC birth traits and presentations.
    - Training of diagnosing healthcare professionals on PWS in BIPOC populations.
    - More POC representation in rare disease photos, leadership, literature and PWSA and FPWR websites.
    - Advocate for newborn screening that includes methylation testing (catch UPD sub-types as well)
    - Connect with typical comorbidity specialists to find undiagnosed older populations (Diabetes clinics, speech therapists, special needs, residential homes and vocational training centers)
- Create targeted and relevant programming with support resources, marketing appropriately
    - Global Registry education and enrollment guidance.
    - Discounts/resources to attend conferences and other learning opportunities.
    - Early access to conferences or retreats. (not on a first come, first served basis)
    - Increase ways for BIPOC to participate in conferences remotely or otherwise
    - Make sure event promotions can reach communities of color and will be convenient and inclusive for them.
    - Consider social media strategies to increase BIPOC outreach, learn best practices from adjacent groups
    - Learn from adjacent groups: Where are other groups finding BIPOC?
- Better communication and support for clinical trials.
    - Make it an industry imperative to include systematic reporting of race/ethnicity in all PWS trials.
    - Create diverse recruitment targets for enrollment
    - Give early and guided access, remembering the trust that needs to be built with these communities.
    - Improve trial follow-up and communication.
    - Virtual sites where nurses travel to patients or do telehealth as much as possible.
    - Consider different incentives to participants of color/most marginalized.
    - Include people of color in the study design, as early as possible.
    - Many industry best practices exist on enhancing diversity in trials and this article outlines some.
- Consider who they want to be connected to?
    - As connections are made, consider connecting folks directly to Colors of Hope to provide community and support relevant to them.

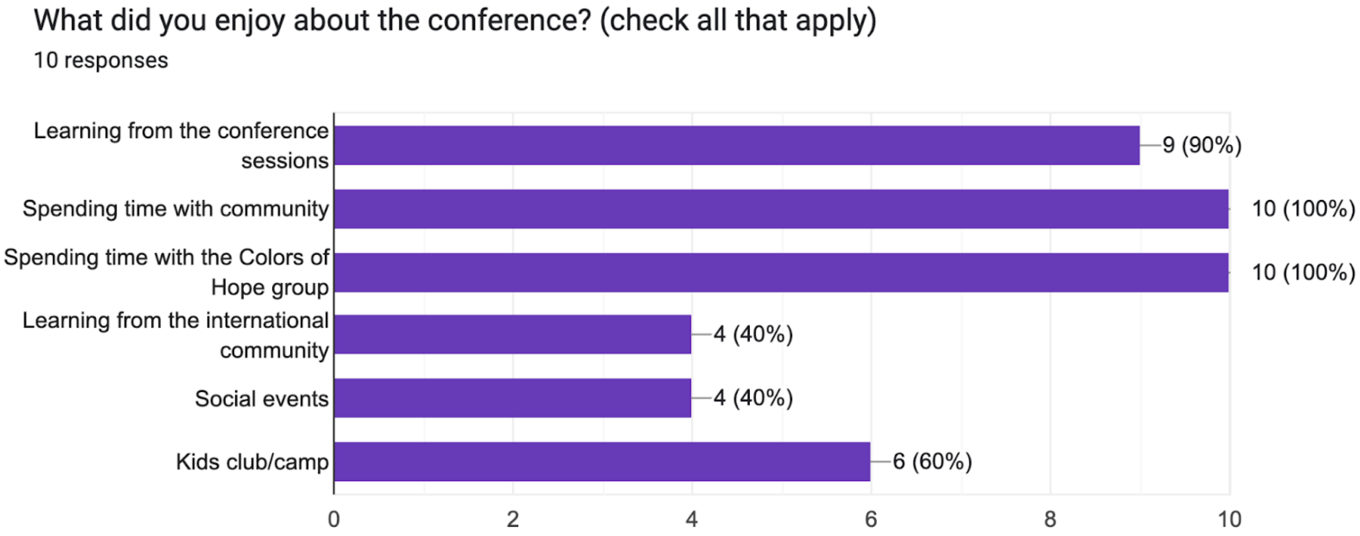
  - Include Colors of Hope information in new diagnosis packets.

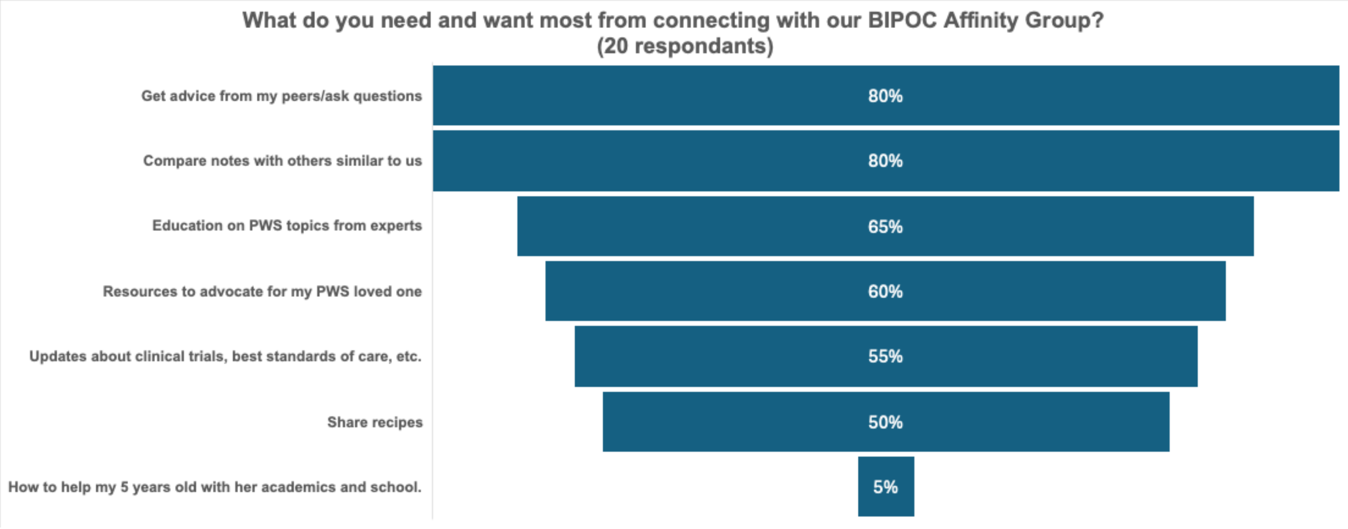
Theme 2: Community Connections

While much of the report focuses on the **unserved needs of the BIPOC community**, we wanted to highlight some of our strengths and values, which we can leverage for solutions.

Strengths and Values of our BIPOC Community

- **Family -** both nuclear and extended families, intergenerational living and learning
- **Culture -** for immigrants and other marginalized and oppressed populations: language,
- food, religion, festivals/holidays, rituals.
- Shared experiences **-** our **common history** allows for natural, easeful relationship building amongst each other sometimes and sometimes oppressive infrastructures create divides.
- We value **time together** with other BIPOC as shown in these charts created by surveying the Colors of Hope group:





Other priorities heard from our community:

- Getting advice from peers/ask questions
- Comparing notes with others similar to me/my loved one with PWS
    - "I would like my son to have **role models/mentors of the same race as him**."
    - "Meet other family with similar ethnicity or culture to provide success and overcome challenges, resources, recommended programs/providers in my state"
    - "To know **how PWS manifests in people of color** and gain ideas around keeping our traditions but also sticking to PWS health restrictions with diet. "
    - "To have people who also **understand** their child not looking "typical" to the PWS image "
    - "We **don't know many other POC with this diagnosis**. Would love to know how/if it affects us differently. Also just nice to have added diversity of people and experiences in this rare syndrome group."
- Education on PWS topics from experts specific to our community
    - "Looking for nutritionist who **understands our food/culture**"
- Raising our voices together
    - "Voices of people of color **need to be heard** especially within the special needs communities "
    - "**better representation**, more outreach to the bipoc community, PWS education & support that addresses the challenges that can come with our different cultures"
- Resources **to advocate** for my PWS loved one (or myself if living with PWS)
- One person wrote in a comment, "I need help on how to get the VYKAT XR prescription expedited."
    - The Colors of Hope group serves to connect folks with the support needed.

In the Colors of Hope **Goals & Focus Areas** section of the Appendix, you can see the steps the Organizers are taking to address these priorities.

Our group has grown to 80 caregivers mainly through word of mouth, social media and relationship building. Participants report having a high value for the group. **We've seen the strength that aligning values and sharing experiences brings**, which is why we wanted to do this report.

Challenge: Food, Family and Gatherings

- Food and community is central to our culture and identity, yet it is one of the most challenging things for PWS families to manage. Many find it easiest to opt out of family gatherings or celebrations, but this comes at a high cost.
    - Cultural issues of how to still celebrate religion or festivals.
- Food creates stress around gatherings and school events where some BIPOC families may already feel isolated as part of a minority population.
- How to remain a part of an extended family - so critical to our communities and it is difficult to get them to understand the challenges of PWS.
- Families question whether to attend activities that are not "PWS friendly."
- As one person stated, "Finding people **who share the same culture as me and look like me and my son gave me another level of support I needed**. Some details about our specific syndrome and especially around changing lifestyle and diet and the stigma around special needs is unique to our culture. We need help from others like us to work through all this."
- Nutritional guidance may not feel doable culturally/financially.
    - "Looking for a nutritionist who understands our food/culture" was one reason people joined the Color of Hope group.
    - Food deserts exist in many places where BIPOC communities reside, making nutritional guidance even harder to manage.
    - One participant said, "Food is culture and culture is food. We speak through food, feel through it and share it. We celebrate, grieve and show love with food. So, asking us to separate food from identity is deeply difficult because food carries our stories and who we are. In my country, you can tell which tribes someone comes from by the food they eat. Food is not just fuel; it's identity. For many elders, food is the primary language of love. When they care for our children, food is how they express that love and that makes these changes especially hard."

➡️ **Needs:** Culturally relevant nutritional guidance, guidance on how to celebrate and practice customs, people/family/communities who understand.

Challenge: Isolation

- PWS Community at large may feel like a "white space" even hostile, it feels like it is assumed we are mooching off the system.
- At times, pushback from the PWS community comes because they feel BIPOC are getting "special treatment" or don't see any lack of equity.

- Importance of support of extended families for people of color and the lack of ways to engage with them. Caregivers sought tools to explain PWS to relatives.
    - Extended families often misinformed (“they will grow out of it”).
- Shame associated with sharing medical complications in many BIPOC communities causes folks to limit interactions.
- Wanting our kids (and us) to feel included in society and the PWS community.
- Importance of having a peer group who look like them:
    - (see comments from the Colors of Hope section and survey results above)
    - On why they wanted to join Colors of Hope:
    - “I would like to connect with this group for cultural diversity to feel like I'm not alone and to share with other parents who are on the same page as me and be able to let the voice of diversity be heard.”
    - “To feel included, get resources and successfully navigate the struggles “

➡️ **Needs:** Culturally relevant resources and multilingual materials for extended families/communities, tools for alleviating shame, peer/affinity groups, more inclusion & belonging work in the community at large.

Of course, isolation is even more of a risk for caregivers who lack time and resources more acutely.

Challenge: Lack of Time/Bandwidth for Caregivers

Many caregivers of color may be single parenting, working several jobs and overall lack resources for support, leaving them in constant survival mode. Not only does this mean it is harder to participate in community events, but sometimes it causes an inability to get adequate care. For example, according to an RDDC Survey Report from 2024, under “factors that may have caused them to delay or forgo care - The most reported barrier was feeling overwhelmed from managing life, care, or caregiving responsibilities” (50% overall compared to 57% of the BIPOC group).[16]

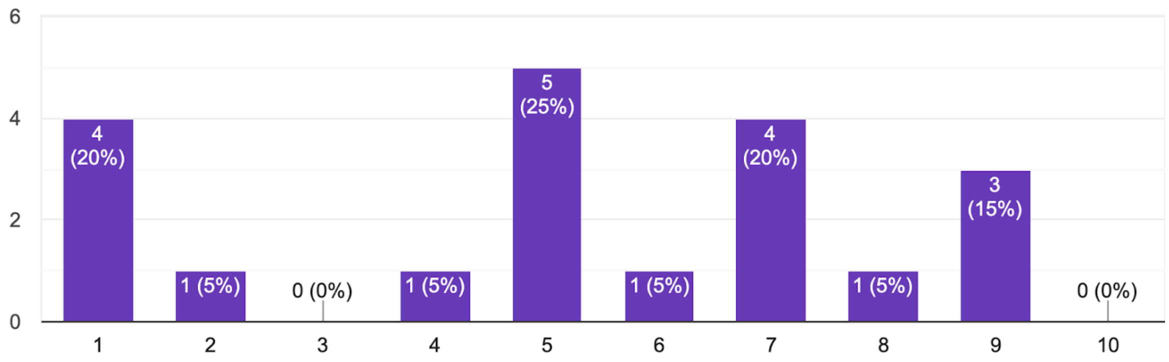
Solutions from the organizations/institutions that require large amounts of time or resources from the community to establish diverse perspectives will fall short.

- High stress burden; need for respite and caregiver wellness support.
    - Particular needs, as often “wellness” spaces carry white centering cultures and practices.
- The first year is particularly hard and just about survival. Caregivers need less to read and do, just more virtual support and hope.
- Hard to reach under-resourced families. (rural, single parent, those living in poverty, just trying to survive)

---

[16] “Inequities in the Rare Disease Community The Voices of Diverse Patients and Caregivers” RDDC and NORD, June 2024, https://rarediseases.org/wp-content/uploads/2024/08/RDDC-Survey-Report.pdf

- The level of support varied a lot even amongst the well-resourced group we surveyed with 4 of those folks rating themselves at a “1” for the least level of support they have to rely upon and “10” for the most support. One would guess that those we haven’t reached yet or didn’t have time to respond would be on this end of the scale as well, so we expect the magnitude of this problem to be severely underrepresented here.


What level of support do you personally have to rely on? (on a scale of 1 to 10)
20 responses

➡️ **Needs:** Respite care, support solutions that are easy and accessible, not time consuming

Community Connection Recommendations:

Food-Related Guidance

- Practical, culturally relevant diet guidance.
- Strategies for handling social gatherings.
- Ongoing tools to keep kids safe around food.
- Culturally relevant advice on food, safety, and social inclusion.
- Community spaces to share recipes.

Support Connection & Safe Spaces

- Establish **culturally safe peer support platforms/services for families to connect with those of similar culture and ages**.
- Foster more connections by language, religion, culture so folks can create their own best practices.
- Safe spaces for diagnosis, learning, grieving, and sharing milestones.
- A place to grieve cultural losses (food traditions, festivals) in culturally affirming ways.
- Provide **multilingual and culturally relevant brochures and videos** tailored to extended families that are easy to share.

- More inclusive educational programming from organizations on how to hold on to cultural customs.
- Create a guide and best practices for overcoming the shame of a diagnosis and include in all new diagnosis packets.

Consider the bandwidth of BIPOC caregivers in outreach:

- Translate materials wherever possible, figure out the intended audience and which languages are most relevant.
- Ask who is missing from the responses and how can we make it simpler for them to participate?
- Modify requirements for marginalized groups
    - Create exception policies for board members, committee members, fly-in attendees, ambassadors, etc to maintain diverse perspectives
- Provide clear resources about registries, support groups, and PWS organizations in places where BIPOC communities live/gather/go.
- Hold events in places more accessible to marginalized groups or consider virtual options for participation and times that don't conflict with the work day.
- Don't use a first-come, first in policy when offering unique opportunities. Think of ways to reserve spaces for less connected, marginalized folks.

Continue supporting/collaborating with Colors of Hope:

- Caregivers crave connection with others who "look like them" and understand their cultural context. Supporting the growth of Colors of Hope will help us reach more of those underserved "missing" people.
    - One could assume that the same is true for individuals living with PWS - affirming their identity is important as well.
- More opportunities for in-person affinity gatherings - host BIPOC retreats/picnics/gatherings.
- Support the Colors of Hope Organizers
    - Travel support - we ourselves or through partners need to be building relationships with clinics, providers and state chapters around the country to reach more people of color.
    - Continued training and mentorship.

Value of Allies

- Allies can amplify voices, expand resources, improve visibility and strengthen outreach.
- We need people who are already in the room to also be aware of and advocate for marginalized communities.
    - Whether reaching out to new researchers, young physicians, teacher groups, etc look to bring a diverse speaking audience and share diverse perspectives.
- Having supporters is meaningful to our community:

    - One respondent said of the BIPOC lunch with health providers included: “Loved it! Particularly appreciate that **the providers joined us and believe in the group**.”

Theme 3 Healthcare Systems:

Challenge: Provider Bias

Aside from the diagnosis challenges listed previously, caregivers also faced day to day challenges when dealing with healthcare providers.

- Parents described needing to **strongly or aggressively advocate** for testing, education, and services—even with resources. They faced combatting stereotypes that they are trying to “mooch off the system.”
- Implicit provider bias can influence diagnostic testing and treatment decisions, resulting in white patients being more likely to receive certain tests.
- Listening Session participants shared experiences of being **dismissed, disbelieved, or treated rudely** by providers.
    - One caregiver stated, “I can’t afford to be angry or difficult because it might negatively impact my child’s care. Instead I have to sit with being disbelieved.”
- This is backed up by data. Amongst African Americans “Nearly a third report that they have experienced discrimination when going to the doctor, according to a poll by NPR, Robert Wood Johnson Foundation and Harvard T.H. Chan School of Public Health.”[17]
    - Black women, for example, are often prescribed less pain medication than white women with the same complaints and are <u>three to four times as likely</u> as white women to die of pregnancy-related causes.[18]
    - “Populations most vulnerable to implicit bias in health care include racial and ethnic minorities, lesbians, gays, bisexual, transgender, and queer (LGBTQ) individuals, children, women, individuals who are overweight or disabled, and those experiencing behavioral health issues.”[19]
- Co-morbidities of people of color may go more undiagnosed.
    - Up to 61% of people with PWS may have a comorbidity according to a study, “Missed Diagnoses and Health Problems in Adults With Prader-Willi Syndrome:

---

[17] Gold, Jenny. “Sickle Cell Patients Suffer Discrimination, Poor Care — And Shorter Lives” KFF Health News, Nov 6, 2017. https://kffhealthnews.org/news/sickle-cell-patients-suffer-discrimination-poor-care-and-shorter-lives/

[18] Cohen, Ronnie. “Affirmative Action Critics Refuse To Back Down in Fight Over Medical Bias Training” KFF Health News, Sept 11, 2025. https://kffhealthnews.org/news/article/dei-critics-medical-affirmative-action-implicit-bias-training-california-ruling/

[19] Reddy, Swapna et al. “Implicit Bias Curricula in Medical School: Student and Faculty Perspectives.” *Health Affairs*. Jan 15, 2020 https://www.healthaffairs.org/content/forefront/implicit-bias-curricula-medical-school-student-and-faculty-perspectives

    Recommendations for Screening and Treatment," in the Journal of Clinical Endocrinology & Metabolism, December 2020.[20]
  - This study from the *Proceedings of the National Academy of Sciences of the United States of America* linked the documented racial bias in pain assessment and treatment to the conditions that remain poorly treated in people of color. It stated, "Specifically, this work reveals that a substantial number of white laypeople and medical students and residents hold false beliefs about biological differences between blacks and whites and demonstrates that these beliefs predict racial bias in pain perception and treatment recommendation accuracy."[21]
- Lack of representation in PWS physicians and specialists of color also leaves patients of color less served. Studies show how care for Black patients is better from Black doctors and that "findings suggest black doctors could reduce the black-white male gap in cardiovascular mortality by 19 percent."[22]

➡️ **Needs:**Healthcare providers that can work with and believe the BIPOC community. Work on educating providers and other healthcare professionals to acknowledge their own implicit biases in order to build trust relationships with patients.

Challenge: Inaccessible Care

Some people we spoke to reported not having access to appropriate care because of distance and financial barriers. The facilitators suggested that this group is probably much larger in the population not surveyed. More research is needed to know what supports would help the most.

Location Barriers:

- The Hospital Survey and Construction Act of 1946 (Hill-Burton Act) granted funding for hospital construction throughout the country however it allowed for racial segregation in hospital access. Today we are still seeing the effects of this on marginalized populations.
  - In research titled, "The Problem Of The Color Line: Spatial Access To Hospital Services For Minoritized Racial And Ethnic Groups" it was found that "Distances to intensive and cardiac care were often longer than thirty miles for rural

---

[20] Pellikaan et al. "Missed Diagnoses and Health Problems in Adults With Prader-Willi Syndrome: Recommendations for Screening and Treatment," *The Journal of Clinical Endocrinology & Metabolism*, Vol 105, Issue 12, Dec 2020. https://academic.oup.com/jcem/article/105/12/e4671/5900721?utm_source=chatgpt.com&login=false

[21] Hoffman, Kelly M., Trawalter, Sophie, Axt, Jordan R., and Oliver, M. Norman. "Racial bias in pain assessment and treatment recommendations, and false beliefs about biological differences between blacks and whites."*Proceedings of the National Academy of Sciences of the United States of America* Vol 113, No. 16. April 4, 2016. https://www.pnas.org/doi/10.1073/pnas.1516047113

[22] Alsan, Marcella, Garrick, Owen, and Graziani, Grant. "Does Diversity Matter for Health? Experimental Evidence from Oakland." *American Economic Review.* Volume 109, No. 12 Dec 2019. https://www.aeaweb.org/articles?id=10.1257/aer.20181446

  high-minority communities. This lack of access was especially severe for American Indian/Alaska Native and Hispanic communities.”[23]
  - “Rural Black communities, all measured variables held constant, were located farther from emergency services, outpatient surgery, ICUs, obstetric care, and cardiac care than rural communities with large White populations.”[24]
- Food access is similarly lower, which has a greater impact on the PWS community: “People from racial and ethnic groups are less likely to have access to food that helps them manage underlying health conditions.”[25]

Financial Barriers:

- “Socioeconomic factors play a significant role, as minorities often experience lower incomes, limited access to health care services and higher poverty rates.”[26]
  - A 2021 American Community Survey showed that Black individuals had an uninsured rate of 9.9%, Hispanic or Latino individuals had a rate of 17.7%, compared to white individuals who had a rate of 6%.[27]
- “Those with lower socioeconomic status often face barriers like limited health insurance coverage, inadequate health care facilities in their communities and financial constraints that prevent them from seeking timely medical care. These barriers can lead to delayed diagnoses, poorer treatment outcomes and ultimately contribute to health disparities.”[28]

There was also a request for the consideration of alternative medicine. It would be helpful to have an assessment of other treatments from around the world

➡️ **Needs:** Appropriate and accessible medical care. Financial support to access care.

Healthcare Recommendations

- Heed Recommendations sent by the PWS Health Equity Initiative to:
  a. Strengthening Partnership, Collaboration, and Sponsorship
  b. Expanding Medical Access
  c. Promoting Culturally Representative and Inclusive Care Models
  d. Contact Parisa Salehi for more info: psalehi@southcentralfoundation.com

---

[23] Eberth, Jan M. et al. ““The Problem Of The Color Line: Spatial Access To Hospital Services For Minoritized Racial And Ethnic Groups” Health Affairs, Vol 41 No. 2, Feb 2022 https://www.healthaffairs.org/doi/10.1377/hlthaff.2021.01409

[24] Horvath, Luke. “Health Equity: Inequitable Access to Healthcare’s Racist Roots” *RTI Health Advance*, March 8, 2022. https://caaccess.org/health-equity-inequitable-access-to-healthcares-racist-roots/?utm_source=chatgpt.com

[25] Odoms-Young et al “Food Insecurity, Neighborhood Food Environment, and Health Disparities: State of the Science, Research Gaps and Opportunities.” *The American Journal of Clinical Nutrition*. 2023 Dec 30;119(3):850–861. doi: 10.1016/j.ajcnut.2023.12.019

[26] “Health Disparities: Creating Health Care Equity for Minorities.” United Way NCA, Sept 24, 2024 https://unitedwaynca.org/blog/healthcare-disparities/

[27] 2021 American Community Survey https://www.census.gov/programs-surveys/acs.html

[28] “Health Disparities: Creating Health Care Equity for Minorities.” United Way NCA, Sept 24, 2024 https://unitedwaynca.org/blog/healthcare-disparities/

    e. A group has convened between FPWR, IPSWO, PWSA USA and COH to work on these initiatives.

- Improve provider awareness of PWS in BIPOC populations, including atypical presentations. Consider Susan Hedstrom’s idea of a ethnic origin “lookbook” to show various presentations visually and an online gallery where those seeking diverse images can find photos to increase representation of BIPOC faces.
- Include panelists and talking points about cultural humility and respectful communication during provider conferences.
- Expand representation of BIPOC physicians - campaign in HBCU and other diverse medical campuses about PWS and research opportunities.
    a. The four HBCUs with medical schools are Howard University College of Medicine, Meharry Medical College, Morehouse School of Medicine and Charles R. Drew University of Medicine and Science
- Expand options for virtual care that is payable by insurance and Medicare and work on cultural acceptance and trust of this modality. Include marginalized populations in the designs of these options, but don’t test run these on a vulnerable population until the bugs are worked out.
- Create blog posts and research studies on non-Western medicine and treatments from around the world.
- Self-advocacy training for people of color facing bias.

Theme 4 Policy and Programs

Challenge: Existing Supports are not known/accessible/relevant

Peer and Social Support

- Peer mentorship was seen as vital but risky if mentors are not adequately trained—untrained guidance could cause harm.
- Availability of BIPOC peer mentors is limited.

School & Professional Support

- Parents in the Listening Sessions described needing to **strongly or aggressively advocate** for testing, education, and services—even with resources.
    - Guidance needs to recognize this unique/more intense struggle
- Disproportionate discipline
    - "Black students are 4 times more likely to experience suspension than their White peers. Because strong disciplinary measures can negatively impact individual student outcomes, **racial inequality in school discipline perpetuates larger racial inequities in economic and educational achievement.**"[29]
    - Many BIPOC communities face biases where they are assumed to have bad behaviors, bad parenting, etc.
    - When combined with PWS behaviors, there can be more misunderstandings and harsher consequences for BIPOC students, leading to poorer educational opportunities.
- PWSA USA school support services have witnessed examples of racist attitudes in IEP meetings.[30]
- Participants wanted more help in acquiring school supports, including transitions and aides.
- Advocacy training for school resources as families of color.

➡️ **Needs:**Train staff for school support meetings in recognizing bias, utilize speakers/experts in overcoming racial bias to help support parents, increase outreach to the BIPOC community about PWSA USA IEP supports, provide resources to bridge the gap between PWS BIPOC parent/student experiences and school staff knowledge, provide mediation services to families needing it for unnecessary disciplinary measures.

Practical Supports - BIPOC Needs:

- Guidance on building support networks.

---

[29] Peterson, Emily "Racial Inequality in Public School Discipline for Black Students in the United States" Ballard Brief - Ballard Center, Fall 2021

[30] PWSA USA CEO Stacy Ward on Dec 22, 2025

- Information/resources for raising children safely.
- Training for group homes and schools.
- More group home availability and options as our children age.
- Help with elopement prevention.
- Acknowledgment of single parenting struggles.
- Professional therapist input for children and caregivers.

➡️ **Needs:** Get existing resources into the hands of BIPOC community members and customize where needed to make them culturally relevant.

Challenge:

- **Program cuts** for Medicaid, Special Education, etc will affect more vulnerable populations more intensely.

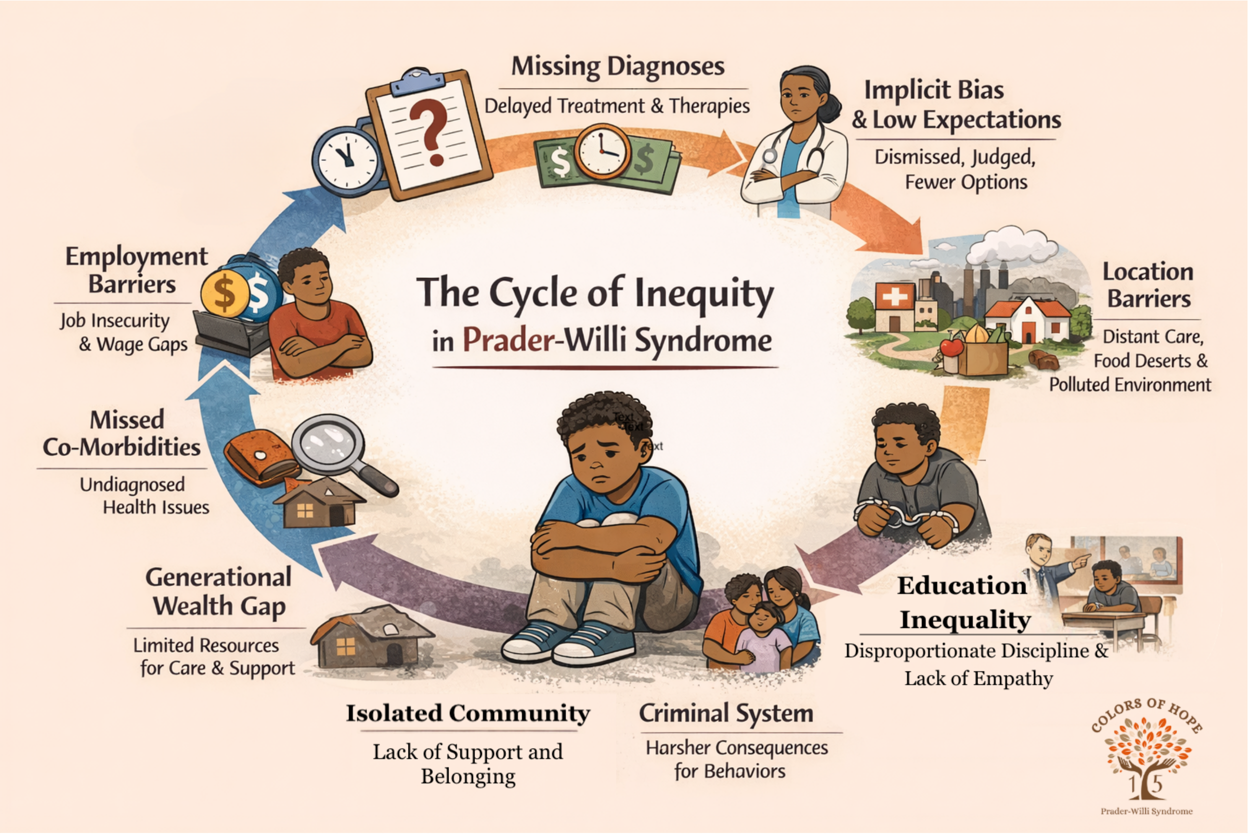
➡️ **Needs:** Policy supports are needed to ensure BIPOC representation in research/clinical trials, much the same way they are needed to promote rare disease research/cures and need similar advocacy.

Policy and Program Recommendations

- All PWS Organizations/professionals need more training in the issues affecting the most marginalized communities and more representation to consider these perspectives in all efforts early on - **don't bring us in as an afterthought**.
- Expand advocacy work to include issues affecting the most marginalized communities affected by PWS.
- Research and clinical trials guidance to include race/ethnicity data, set diversity targets and include BIPOC perspectives in study designs.
- Make advocacy work more accessible to BIPOC, including lesser time and financial resources required.
    - Consider the risks people of color face to do advocacy work and face hostile government workers or politicians. How can we advocate alongside?
- Train all ambassadors/advocates in talking points for the entire community including BIPOC.
- Offer self-advocacy solutions to the BIPOC community, including their needs.
- Fund culturally relevant peer mentor training.
- Train all support staff including conference and camp staff on inclusion strategies.
- Expand school supports, including resources for transition planning.

Compounding Effects = Cycle of Inequity

All of these factors and more compound to create an untenable situation for BIPOC families affected by PWS. While lack of resources or rural locations may be present in many populations including white families, that is just one piece of the machine holding back Black/brown folks. When you take into consideration starting with a late diagnosis and then facing bias in healthcare interactions, being located away from care and healthy food options, then facing systemic racism present in our school to prison pipeline, on top of the isolation from our communities, with the compounding factors of being descendents of slaves or colonized people and on and on, then one cannot deny the unbearable and unique burden that families of color with Prader-Willi face. These factors shown in the chart below are just some of the many differences that people of color face that all combine to make PWS an even harder journey.



Breaking the cycle will require a holistic approach to address the many social causes of inequity and targeted, culturally relevant solutions that are not color blind.

Recommendations Summary

Resources/tools must be customized for the BIPOC community and be culturally relevant. A color-blind, standard approach to all leaves the most vulnerable at risk and under-served.

RECOMMENDATIONS

People & Research: Action Steps

01

Expand Diagnosis Pathways

Research BIPOC birth traits, train providers, advocate for newborn screening

02

Partner with Trusted Organizations

Work with medical associations, clinics, community health workers

03

Create Targeted Programming

Relevant resources, appropriate marketing, early conference access, Global Registry education and enrollment

04

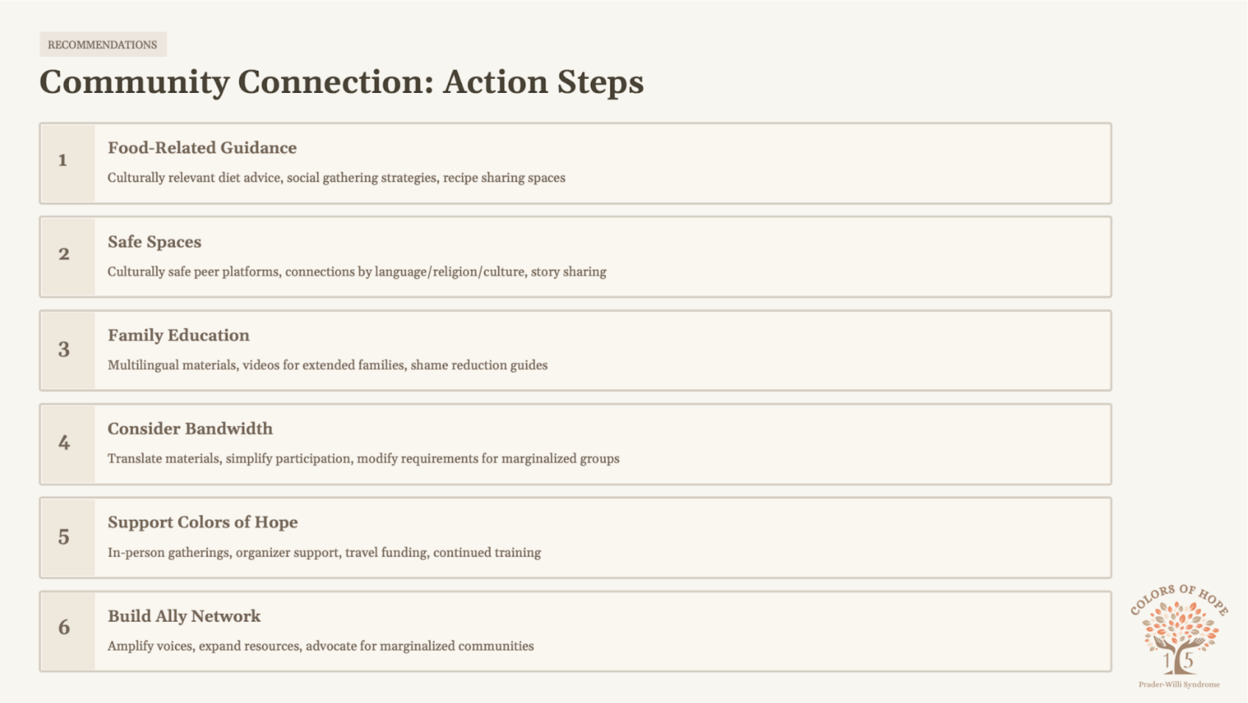
Improve Clinical Trial Access

Systematic race/ethnicity reporting, diverse recruitment targets, virtual options

05

Connect to Colors of Hope

Include information in new diagnosis packets



RECOMMENDATIONS

Community Connection: Action Steps

1 **Food-Related Guidance**
Culturally relevant diet advice, social gathering strategies, recipe sharing spaces

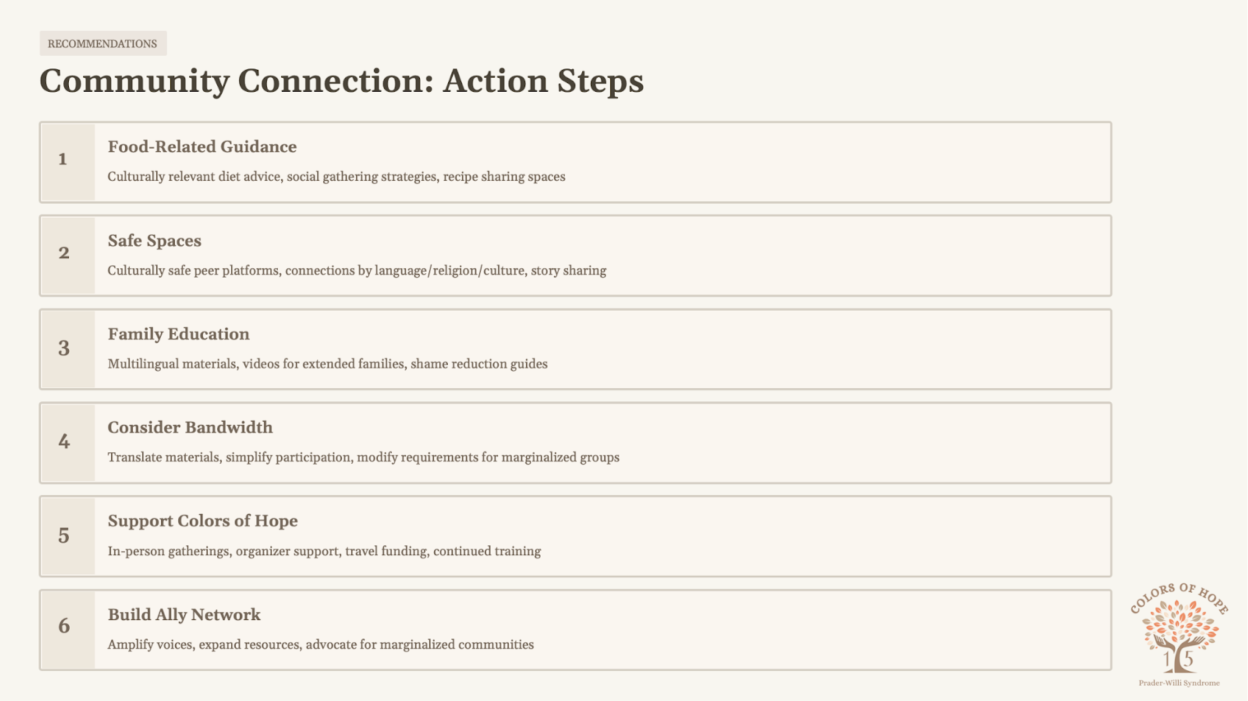
2 **Safe Spaces**
Culturally safe peer platforms, connections by language/religion/culture, story sharing

3 **Family Education**
Multilingual materials, videos for extended families, shame reduction guides

4 **Consider Bandwidth**
Translate materials, simplify participation, modify requirements for marginalized groups

5 **Support Colors of Hope**
In-person gatherings, organizer support, travel funding, continued training

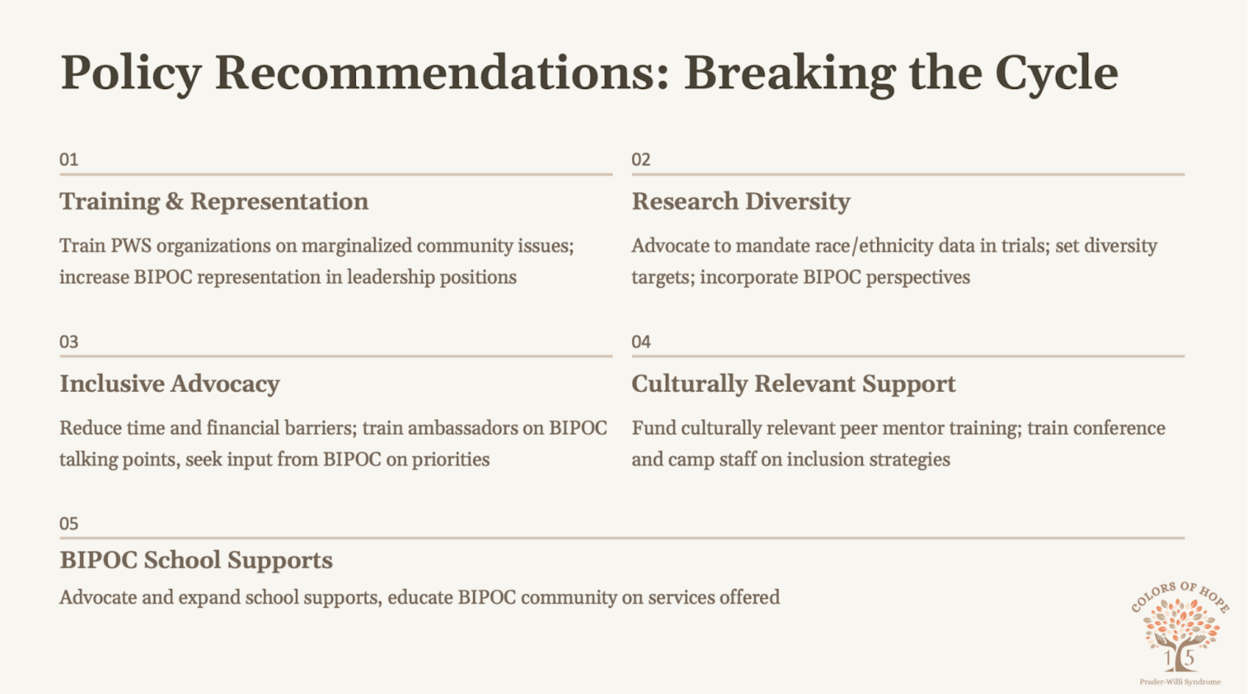
6 **Build Ally Network**
Amplify voices, expand resources, advocate for marginalized communities



RECOMMENDATIONS

Community Connection: Action Steps

1. **Food-Related Guidance**
   Culturally relevant diet advice, social gathering strategies, recipe sharing spaces
2. **Safe Spaces**
   Culturally safe peer platforms, connections by language/religion/culture, story sharing
3. **Family Education**
   Multilingual materials, videos for extended families, shame reduction guides
4. **Consider Bandwidth**
   Translate materials, simplify participation, modify requirements for marginalized groups
5. **Support Colors of Hope**
   In-person gatherings, organizer support, travel funding, continued training
6. **Build Ally Network**
   Amplify voices, expand resources, advocate for marginalized communities



Policy Recommendations: Breaking the Cycle

01

Training & Representation

Train PWS organizations on marginalized community issues; increase BIPOC representation in leadership positions

02

Research Diversity

Advocate to mandate race/ethnicity data in trials; set diversity targets; incorporate BIPOC perspectives

03

Inclusive Advocacy

Reduce time and financial barriers; train ambassadors on BIPOC talking points, seek input from BIPOC on priorities

04

Culturally Relevant Support

Fund culturally relevant peer mentor training; train conference and camp staff on inclusion strategies

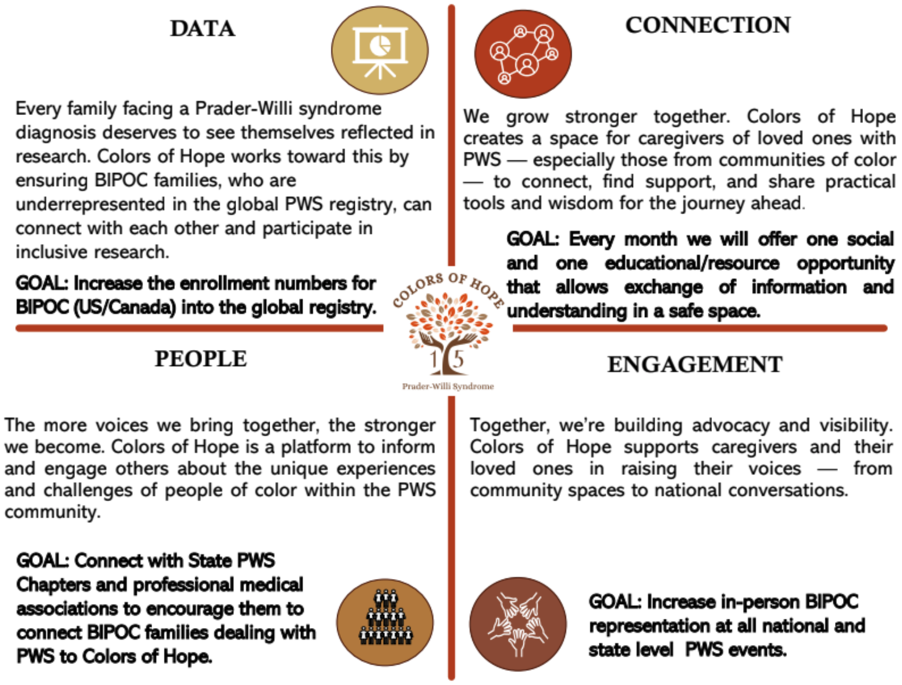
05

BIPOC School Supports

Advocate and expand school supports, educate BIPOC community on services offered

These recommendations align well with the 2026 goals for the Colors of Hope organizers outlined below.

Colors of Hope 2026 Goals & Areas of Focus



DATA

Every family facing a Prader-Willi syndrome diagnosis deserves to see themselves reflected in research. Colors of Hope works toward this by ensuring BIPOC families, who are underrepresented in the global PWS registry, can connect with each other and participate in inclusive research.

GOAL: Increase the enrollment numbers for BIPOC (US/Canada) into the global registry.

CONNECTION

We grow stronger together. Colors of Hope creates a space for caregivers of loved ones with PWS — especially those from communities of color — to connect, find support, and share practical tools and wisdom for the journey ahead.

GOAL: Every month we will offer one social and one educational/resource opportunity that allows exchange of information and understanding in a safe space.

PEOPLE

The more voices we bring together, the stronger we become. Colors of Hope is a platform to inform and engage others about the unique experiences and challenges of people of color within the PWS community.

GOAL: Connect with State PWS Chapters and professional medical associations to encourage them to connect BIPOC families dealing with PWS to Colors of Hope.

ENGAGEMENT

Together, we're building advocacy and visibility. Colors of Hope supports caregivers and their loved ones in raising their voices — from community spaces to national conversations.

GOAL: Increase in-person BIPOC representation at all national and state level PWS events.

Progress Made as of Dec. 2025

As the Organizers of Colors of Hope were convening in 2024, some industry leaders wondered whether anything could be done to find more people of color. While it isn't easy, progress can and has been made with targeted, BIPOC led and informed efforts.

- The Colors of Hope affinity group formed in April 2024 and as of the end of 2025, the email list was up to 80 caregivers.
- A Taskforce group between Colors of Hope, PWSA USA and FPWR formed and convenes monthly to **align on conferences, scholarships, and other initiatives**.
- **New Audience**: Many of the members of the Colors of Hope group are new to the established groups and were not active with either organization previously.
- Helping outreach become inclusive: Colors of Hope was invited by PWSA USA to speak to the state chapters and had a follow up conversation with the FL state chapter.
    - As a result of this connection, the FL state chapter website is now in Spanish and a Spanish-speaking Colors of Hope Organizer will attend their Miami Zoo event to pass out flyers and make connections.
- The Colors of Hope group has focused on the conference experience for BIPOC:
    - Assisted and spread the word about scholarships for conference attendees
    - Held pre-conference Zoom to answer questions and encourage attendance
    - Offered Colors of Hope T shirts in advance of conference
    - Held in-person meetups at the conference: Thursday dinner, Saturday lunch, Sunday breakfast and participated in panels
    - Sent a post conference survey and shared learnings with non-attendees
        - Those BIPOC who attended FPWR Atlanta - several said it was their first conference
    - Results: While data was not collected before on representative attendance (which is data by itself) attendance at United in Hope 2025 was nearly 20% BIPOC, which Colors of Hope organizers anecdotally report as much higher and more visible than any past conference.
    - Appreciated by our community:
        - "Appreciate the professional facilitation, advocacy to have these meetings and the connection."
        - "I enjoyed the talk session, and I'm open to attending another. It was refreshing to be in a group of knowing individuals."
        - "Your work is so important and I truly value what you all are doing even though I don't participate as much as I should!"
        - "Thank you for making sure the BIPOC community is seen, heard, and represented in our small rare disease community. Your work is meaningful to families and very much appreciated."
        - "It was wonderful to meet other families of color dealing with similar experiences having children with PWS. I felt less isolated being a part of this group. I love the advocacy and the steps being taken to make sure people of color are seen and heard."

Takeaway: with focused and culturally mindful efforts, progress can be made in outreach and attendance.

Next Steps

- Conduct broader validation surveys with trusted BIPOC-focused organizations. (Equity Committee)
- Partner with clinics, state orgs and local health systems to reach under-represented groups. (ALL)
- Work with PWSA USA to create culturally responsive peer mentor training that is not a burden on the receiver. (PWSA USA and Colors of Hope)
- Bring in outside trainers/consultants to bring cultural sensitivity and awareness of the needs of these communities to leadership of both FPWR and PWSA USA. (ALL)
- Develop a toolkit for family education (multilingual, culturally relevant). (PWSA USA)
- Report back findings to participants and other stakeholders to ensure accountability and transparency. (Equity Committee)
- Continue partnership with FPWR to increase awareness about the Global Registry and the necessity of representation within ALL clinical trials, research initiatives and studies.
- Make sure the Colors of Hope Mission, Vision and Goals are aligned with community needs, strengths and values. See appendix with Colors of Hope Goals and Areas of Focus. (Colors of Hope)

Gratitude, thank you to:

The Colors of Hope Organizer team - I am privileged to work with some of the best people on Earth and so grateful to the co-organizers Karine, Charles, Gennelle and Sarah whose hard work to build relationships, provide vision and feedback, and add soul is incredibly inspiring. We are all parents, volunteers and passionately committed. Thank you for the true teamwork!
Survey and Listening Session participants - we are honored that you chose to share your stories with us and forever grateful to you for your time and faith. .
I AM ALS facilitators - Aditi Narayan Minkoff and Michael Lecker not only led our sessions with compassion and expertise, but they also mentored us in the early stages of our organizing.
Soleno team - thank you to Jill and the many others who believe in equity and have been partners with us on this project from the start.
Acadia Team - we are grateful for your sponsorship of this important initiative. Best of luck!
Rare Disease Diversity Coalition - thank you for your mentorship and encouragement!
Stacy Ward of PWSA USA - thank you for collaborating with us and taking the reins with such gusto! We see your enthusiasm and are encouraged by the partnership.
Susan Hedstrom, Melissa Demand of FPWR - Susan, you suggested we take the lead on leading our community forward and we thank you for that encouragement. We are grateful to you and Melissa for the way you look to make diversity and representation a reality.

Appendices

- Resource List

Resource List:

Undoing Racism Workshops

So you want to talk about Race by Ijeoma Oluo (book)

Seeing White podcast

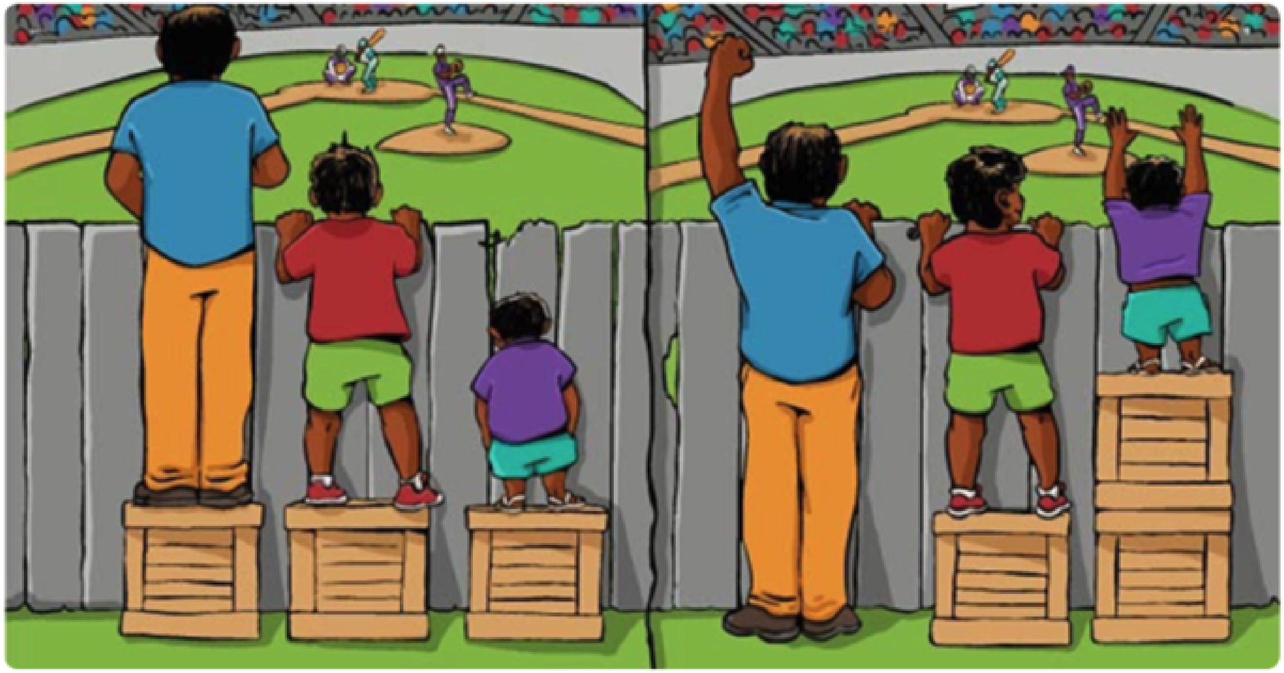
The myth of race, debunked in 3 minutes (video)

Why Color Blindness Will NOT End Racism (video)

Inclusion and Diversity in Clinical Trials: Actionable Steps to Drive Lasting Change (PubMed)

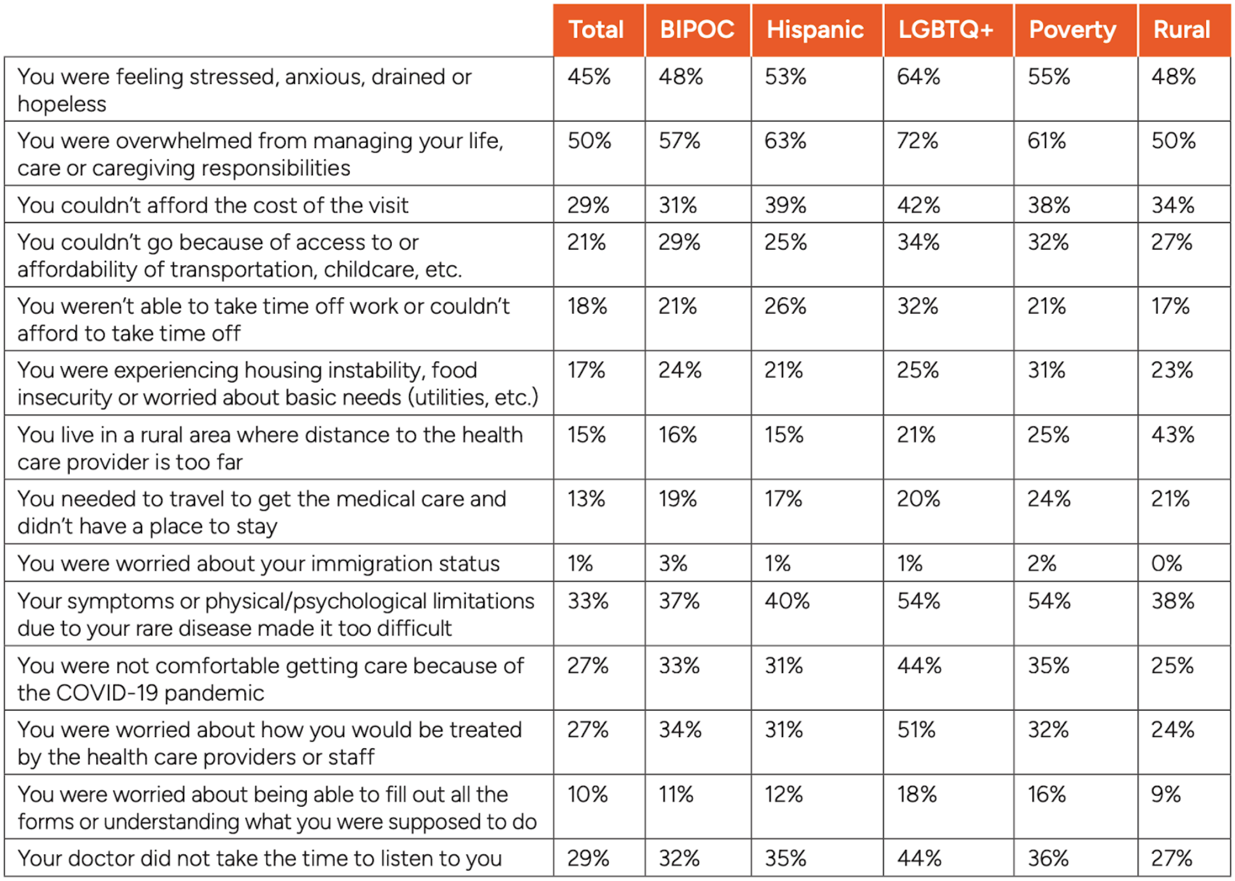
Rare Disease Diversity Coalition (organization)

Equity v. Equality (diagram below)



Interaction Institute for Social Change | Artist: Angus Maguire

Source RDDC survey[31], factors that may have caused them to delay or forgo care:



	Total	BIPOC	Hispanic	LGBTQ+	Poverty	Rural
You were feeling stressed, anxious, drained or hopeless	45%	48%	53%	64%	55%	48%
You were overwhelmed from managing your life, care or caregiving responsibilities	50%	57%	63%	72%	61%	50%
You couldn't afford the cost of the visit	29%	31%	39%	42%	38%	34%
You couldn't go because of access to or affordability of transportation, childcare, etc.	21%	29%	25%	34%	32%	27%
You weren't able to take time off work or couldn't afford to take time off	18%	21%	26%	32%	21%	17%
You were experiencing housing instability, food insecurity or worried about basic needs (utilities, etc.)	17%	24%	21%	25%	31%	23%
You live in a rural area where distance to the health care provider is too far	15%	16%	15%	21%	25%	43%
You needed to travel to get the medical care and didn't have a place to stay	13%	19%	17%	20%	24%	21%
You were worried about your immigration status	1%	3%	1%	1%	2%	0%
Your symptoms or physical/psychological limitations due to your rare disease made it too difficult	33%	37%	40%	54%	54%	38%
You were not comfortable getting care because of the COVID-19 pandemic	27%	33%	31%	44%	35%	25%
You were worried about how you would be treated by the health care providers or staff	27%	34%	31%	51%	32%	24%
You were worried about being able to fill out all the forms or understanding what you were supposed to do	10%	11%	12%	18%	16%	9%
Your doctor did not take the time to listen to you	29%	32%	35%	44%	36%	27%

---

[31] "Inequities in the Rare Disease Community The Voices of Diverse Patients and Caregivers" RDDC and NORD, June 2024, https://rarediseases.org/wp-content/uploads/2024/08/RDDC-Survey-Report.pdf