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BRIEF REPORT

From Genomes to Conversations: Outreach and Engagement in Psychiatric Genetics

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Abstract

Outreach in psychiatric genetics bridges the gaps across research advancements, clinical practice, and public understanding. Effective communication with a range of audiences faces multiple challenges, including the complex nature of psychiatric disorders and of genetic findings, the chronicled and ongoing misuse of genetic data, and the rapid growth of direct-to-consumer genetic testing. This is particularly true in the internet and social media era, which has accelerated the spread of inaccurate information with serious consequences, including perpetuating stigma and increasing shame. Yet a significant gap remains in outreach: a recent survey found that only 51% of psychiatric genetics researchers participate in outreach, largely attributed to their perceived lack of skill and support. The Psychiatric Genomics Consortium (PGC) developed an Outreach Committee to organize and catalyze initiatives including: the Worldwide Lab, an online seminar series covering new and important approaches that is then posted on YouTube; the PGC Video Textbook, which has resources for clinicians, researchers, educators, and the broader public; patient and family engagement programs; and social media campaigns designed to inform both researchers and affected communities about new developments in psychiatric genetics. These initiatives were developed to demystify psychiatric genetics research and empower broad audiences with reliable, actionable information. Along with research and traditional teaching, the psychiatric genomics community should continue to prioritize and recognize engagement as a core component of our academic mission and values.

Keywords Psychiatry · Genomics · Outreach · Community · Communication

Introduction: What is Outreach and Why Do We Need It?

> Our most direct and urgent message must be to the scientists themselves: learn to communicate with the public, be willing to do so and consider it your duty to do so.
>
> (Bodmer 1986).

The field of psychiatric genetics is uniquely complex, shaped by the convergence of two domains often burdened with misunderstanding: psychiatric illness, which remains heavily stigmatized (Morgan et al. 2018), and genetics, which is plagued by misinterpretation, often in the form of genetic determinism (Harden 2022). Combined, the potential for misinterpretation is magnified (Morosoli et al. 2021; Peck et al. 2022). This challenge is intensified by the past (Rutherford 2022) and contemporary (Carlson et al. 2022) misuse of genetic data, as well as the rapid growth of direct-to-consumer genetic testing (Jiang et al. 2023). Over the last decade, social media platforms such as X (formerly Twitter), Bluesky, TikTok, Instagram, and Facebook have transformed how information is shared and consumed. Social media can provide numerous benefits, such as easy access to support groups, efforts to destigmatize mental health conditions, and the rapid dissemination of content across borders

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Extended author information available on the last page of the article and demographics. However, this same speed has also accelerated the spread of inaccurate or misleading information, particularly around complex, sensitive topics such as genetics and mental health. Similarly, the rise of non-expert, influencer-driven content and the pursuit of online visibility or 'clout' has contributed to a culture in which sensationalism can be rewarded over scientifically-accurate content (Aragon-Guevara et al. 2023; Starvaggi et al. 2024). Like many scientists, researchers in psychiatric genetics often face uncertainty about how to communicate their findings in a way that retains both accuracy and accessibility (Brownell et al. 2013; Middleton et al. 2023). The consequences of misinformation in psychiatric genetics are significant. Stigma and shame related to mental health, already pervasive in many communities, are easily reinforced by widely shared but inaccurate narratives (Nour et al. 2017) that often rely on societal norms and reinforce stereotypes (Starvaggi et al. 2024). This is exacerbated by the relatively limited public engagement by experts, whose voices are often drowned out by the volume and virality of social media content and misrepresentations of science in some mainstream media. This dynamic poses a unique challenge for researchers and advocates in psychiatric genetics who are working to build public understanding and trust.

Effective scientific outreach in the field of psychiatric genetics is more urgent now than ever (Besterman et al. 2025). "Outreach" encapsulates a range of activities with the core aim of sharing accurate information across different groups to improve awareness, perception, and understanding. Whilst there is no clear consensus on where "research" ends and "outreach" begins (Kassab 2019), in this article we define outreach in psychiatric genetics as engaging with other researchers, clinicians, patients, and the general public not only to disseminate information but also to receive feedback and knowledge from our audiences. Strategic communication that highlights the role of both genetics and the environment can steer understanding away from genetic determinism (Jamieson & Radick 2017) and can counter stigma (Austin & Honer 2007; Michael et al. 2020). By tailoring information to audiences with varying levels of expertise, we can highlight genetics research as a pathway to greater understanding, compassion, and therapeutic innovation, rather than as a means of labeling or pathologizing individuals. Proactive acknowledgment of the fraught legacy of psychiatric genetics can foster trust, promote ethical transparency, and demonstrate how modern research prioritizes informed consent and advancing health outcomes for *all* individuals (Canfield et al. 2020). Importantly, clear messaging can reinforce that biological vulnerability to psychiatric illness is not a personal failing (Inglis et al. 2015), and that tools such as polygenic risk scores must be interpreted with nuance and within appropriate contexts (Choi et al. 2020).

Numerous factors, including researcher preferences, language differences, and cultural context, can influence both how psychiatric geneticists conduct their own research and their receptiveness to fellow scientific endeavors (Bautista et al. 2022). Communication among scientists commonly takes the form of conferences and academic publications, the costs of which can be prohibitive to some (Bautista et al. 2022). Certain culture-specific concepts related to mental health may be poorly captured by English translations, which can limit effective cross-cultural communication. For clinicians, keeping up with the rapid pace of discovery in genetics research and understanding its clinical relevance can be overwhelming, particularly in professions where genetics training is limited (Besterman et al. 2025; Bulik 2024).

Established in 2007, the Psychiatric Genomics Consortium (PGC) is the world's largest collaboration studying the genetic basis of psychiatric conditions. Comprising approximately 1,770 scientists from more than 60 countries, the PGC is organised into multiple working groups (https://pgc.unc.edu/for-researchers/working-groups/). Recognizing the issues above, the PGC founded the Outreach Committee in 2016 with support from a National Institute of Mental Health (NIMH) grant supplement focused on dissemination and outreach. This initiative brings together individuals with different scientific backgrounds and lived experiences to improve the visibility, accessibility, and understanding of psychiatric genetics. This NIMH grant enabled the PGC to hire a Dissemination Research Assistant on a short-term basis to initiate various communication tools, including a range of social media profiles, the "For the Public" page on the PGC website, and short informative videos about the research aims of the PGC groups. The PGC Outreach Committee aims to engage broad audiences, from the wider scientific and clinical community to the general public, through accurate, responsible, and transparent communication of psychiatric genetics (Fig. 1) and participation in bi-directional dialogue that focuses on learning with and from each other (Reincke et al. 2020). This paper presents an overview of activities we consider valuable, including examples of how we are implementing them, as well as plans for the future.

Identifying the Gaps Within the Psychiatric Genetics Community

Despite the increasing importance placed on participating in outreach activities, the interest and uptake in these initiatives among psychiatric genetics researchers remained

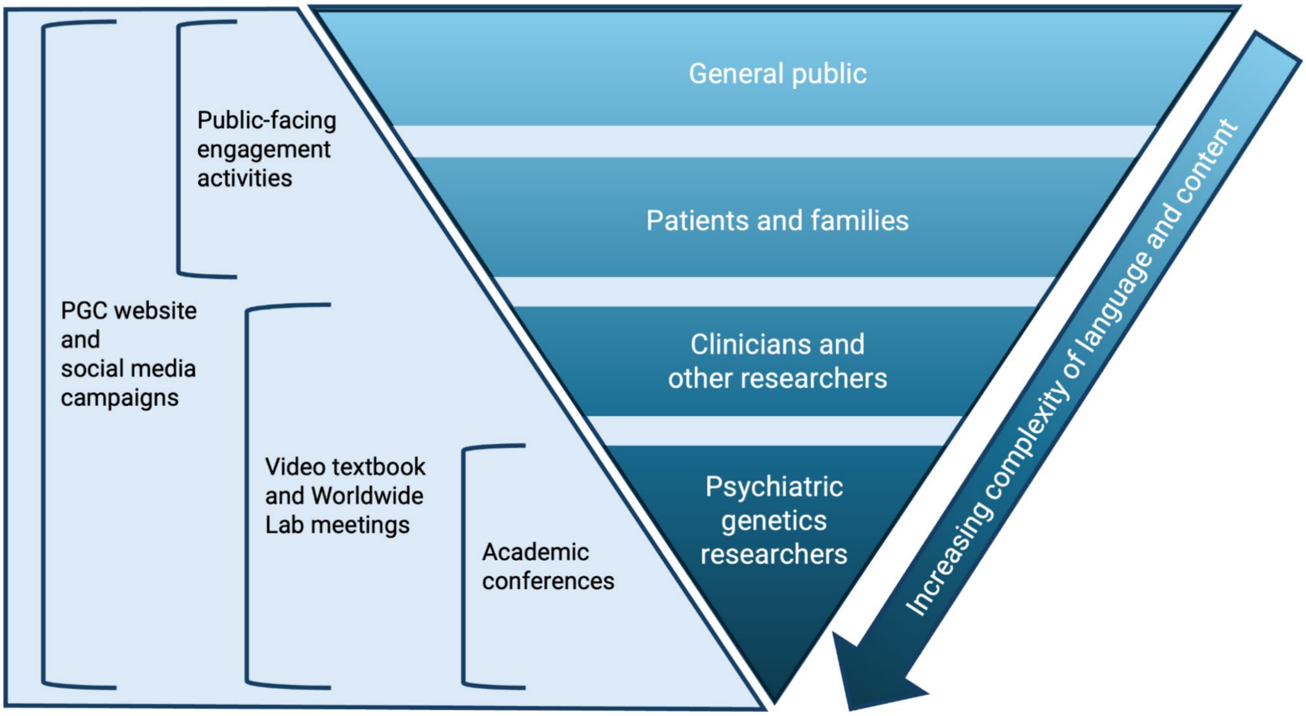


Fig. 1 The PGC Outreach Triangle. This model illustrates the PGC's tiered approach to scientific outreach, tailored to audiences with varying levels of expertise by adjusting content complexity and delivery strategies. The outreach activities shown on the left aim to enhance accessibility, encourage dialogue, and build trust among various stakeholder groups.

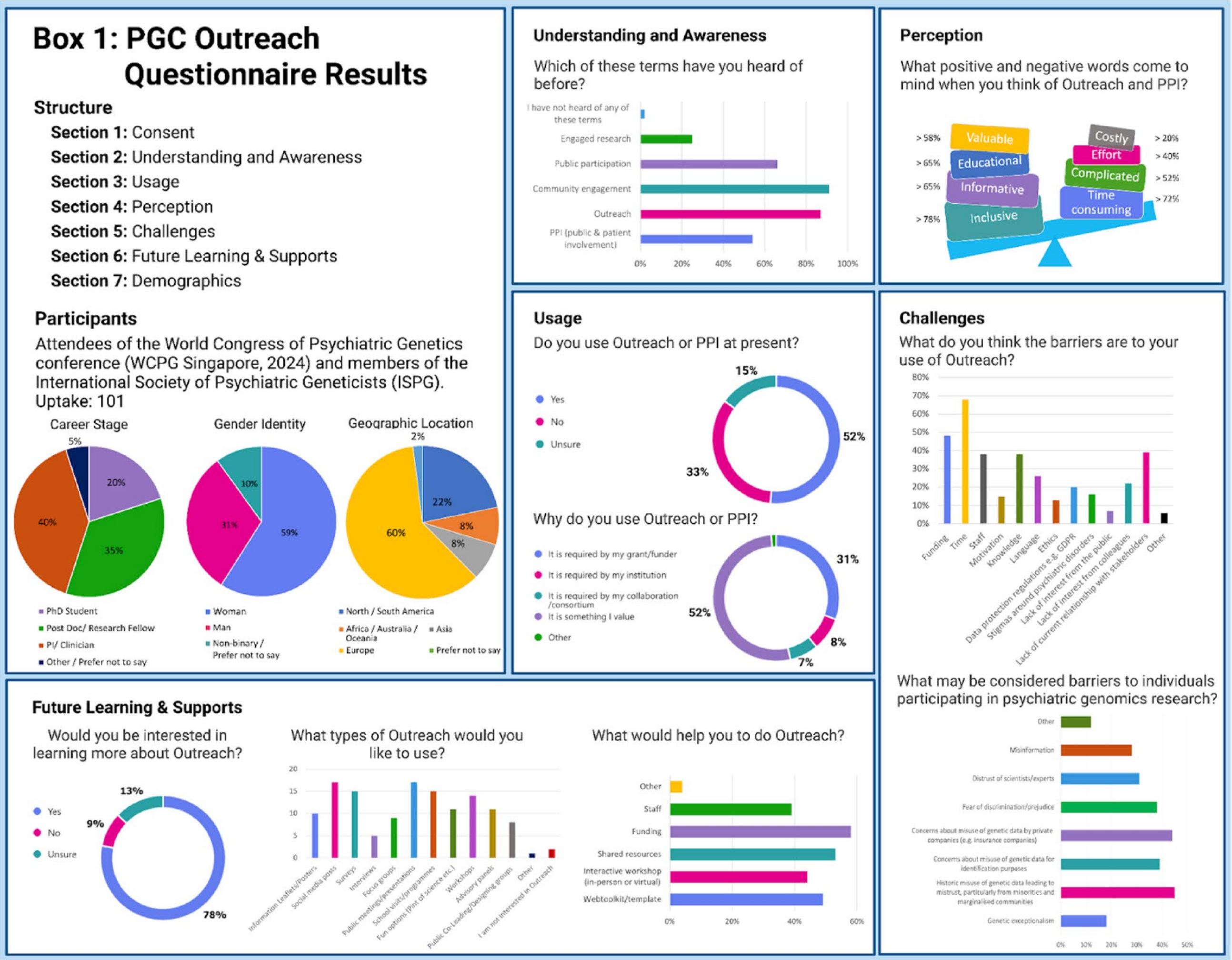
unclear. To gain insight into the awareness, perception, and utilization of outreach and Patient & Public Involvement (PPI) by the psychiatric genomics community, the PGC Outreach Committee developed a questionnaire that was shared with attendees at the World Congress of Psychiatric Genetics (WCPG) in Singapore (October 2024) and members of the International Society of Psychiatric Genetics (ISPG) by email (n=1,284; of which 663 attended WCPG 2024). This questionnaire was divided into six main sections to explore specific themes: (1) Understanding and Awareness, (2) Usage, (3) Perception, (4) Challenges, and (5) Future Learning & Supports, and (6) Demographics (Box 1; and Supplementary Data).

Participants (n=101) spanned career stages and included members from the global psychiatric genomics community, though primarily based in Europe. Results showed that participants were broadly familiar with terms like "*Outreach*" and "*Community Engagement*," but demonstrated notably less understanding of "*PPI (Public and Patient Involvement)*" and related concepts. Nearly half of the respondents reported currently engaging in outreach, one third indicated they were not currently engaging in outreach, and the remaining participants said they were unsure if they use it, highlighting the lack of clarity on the topic and the potential for confusion. Participants generally held a positive view of outreach, considering it to be educational and impactful. Concerns about the past mistrust in psychiatric genetics and a perceived lack of necessary skills, time, and funding to engage in outreach were noted as major challenges. Most participants expressed interest in learning more about outreach and PPI, especially through workshops, videos, and shared resources. These findings have highlighted which tools are considered most useful for supporting outreach activities within the psychiatric genetics community. The results of this questionnaire will help guide future aims of the PGC Outreach Committee.

PGC Toolkit for Strategic Outreach

Academic Conferences

The WCPG offers a unique opportunity to engage with the broader psychiatric genetics community. Enabled by the aforementioned NIMH grant supplement, the 2017 WCPG conference in Orlando, Florida, featured a full-day media workshop led by an experienced journalist with expertise in science communication, equipping participants with the tools to "think like a reporter" and improve their chances of securing media coverage. The workshop provided a deep



Box 1 Summary of the PGC Outreach Questionnaire results. Each sub-box highlights the main results from the six sections: Demographics, Understanding and Awareness; Usage; Perception; Future Learning and Supports; and Challenges. Created in BioRender. (Ryan, 2025)

dive into the influence of social media, explored how journalists engage with these platforms, and offered practical strategies for researchers to effectively share their work in digital spaces. For WCPG 2022 in Florence, Italy, members of the PGC Outreach Committee collected quotes from their respective patient groups on why they think psychiatric genetics research is important. These quotes were displayed throughout the conference to give researchers insight into the lived experiences of the conditions they study and to humanize the participants behind the datasets they work with every day. The PGC Outreach Committee held a symposium at the 2024 WCPG in Singapore focused on science communication (Davies et al. 2024). Four expert speakers shared their insights on the dynamic interplay among language, empathy, and engagement in effective science communication. Topics included bridging linguistic and cultural divides, unconscious influences on how people process information about genetics, the formation of culturally sensitive narratives from complex scientific concepts, and strategies for responding to misappropriations of genetics research. The event concluded with a panel discussion in which the speakers shared practical strategies for combating misinformation and making complex ideas accessible to a broader audience.

Video Textbook

The PGC video textbook was launched in October 2023 as a collaborative effort led by PGC members from different countries, disciplines, and experiences. This open-access training program combines online resources into a structured format, hosted on the PGC GitHub (https://pgcanalytic s.github.io/pgcvideotextbook/). Organised into chapters, the textbook covers key areas of psychiatric genetics including background information, software, methods training, and even accessible explanations like "GDPR for Dummies", allowing users to tailor their own learning paths. Each resource is summarised with information on video length and difficulty level (basic, intermediate, or advanced), with links to journal papers. Transcripts are provided, including a Portuguese translation.

Worldwide Lab Meetings

As part of the PGC's mission to support open, accessible, and participatory science, an initiative was launched in 2012 to improve the communication of the latest findings and approaches in psychiatric genetics to researchers. PGC Worldwide Lab Meetings (WWL) are live-streamed webinars that are recorded and then uploaded to the publicly available PGC YouTube channel. These webinars are currently held monthly and showcase the range of research conducted by PGC members and others pursuing related work. As an example, in late 2024, the PGC Outreach Committee held a WWL to discuss the importance of outreach in psychiatric genetics.

Social Media Campaigns

The PGC Outreach Committee has used social media to engage both scientific and public audiences. The YouTube channel contains almost 150 educational videos and has over 1,500 subscribers (@psychiatricgenomicsconsort2267). It includes recordings of the WWL so researchers who are unable to attend the live presentation (including those in other time zones) can access the information. The PGC X account (@PGCgenetics), launched in January 2017, has become a consistent tool for sharing research highlights and updates. With over 5,600 followers, the account helps communicate PGC outputs in accessible formats, reaching beyond academic circles. More recently, the PGC has also launched a Bluesky account (@pgcgenetics.bsky.social)—due to the gain in popularity of this platform—as well as an Instagram account (@pgcgenetics), to reach a broader audience beyond the primarily peer-focused platforms of X and Bluesky.

A key strength of social media is that it provides open access to scientific findings, bypassing the paywalls typical of academic journals and enabling people who might not seek out the research to learn about key findings. The PGC has organized this outreach effort by having different PGC working groups manage the account for two weeks per year to showcase their work, while also encouraging postings of findings from other groups. Posts often feature recent publications, infographics, graphical abstracts, new initiatives, broader updates, and educational materials that might not otherwise reach the public.

PGC Website

At its core, PGC-related outreach is anchored by a user-friendly website, launched in 2012, initially designed to showcase PGC efforts and make them accessible to researchers as a learning resource. Since its inception, the platform has offered researchers comprehensive information about the full scope of PGC activities, who to contact if they are considering joining, and a step-by-step pipeline for accessing genome-wide summary statistics. This has contributed significantly to the expansion of the PGC network and increased the use and value of the group's data. Recognizing the need for outreach efforts noted above, the website was expanded to engage all levels of the outreach triangle (Fig. 1) by offering dedicated pages "For researchers": https://pgc.unc.edu/for-researchers/, "For clinicians": https://pgc.unc.edu/information-for-clinicians/, and "For the public": https://pgc.unc.edu/for-the-public/ that provide educational content on key genetic topics tailored to each audience.

Public-Facing Activities

Members of the PGC undertake a wide range of patient, family, and public engagement activities. Whilst an in-depth review of such activities is beyond the scope of this commentary, we highlight three recent examples to demonstrate the dynamic forms these efforts take. First, a PGC member discussed the benefits of genomic sequencing, particularly for psychiatric disorders, at *Pint of Science Ireland* (https://pintofscience.ie/)—a global not-for-profit event in which scientists from different fields informally present their research in bars, pubs, or cafes. Second, during Denmark's first *Eating Disorder Awareness Week* event, another PGC member gave a talk about eating disorder genetics to patients and families (Davies & Washbrook 2024). The third example demonstrates an innovative leveraging of popular culture in science communication: members of the PGC participated as panel members at the 2025 *Edinburgh Fringe Stand-Up Science* show. These are a small sample of public-facing ways in which psychiatric genetics researchers are actively engaging public audiences in dynamic knowledge exchange.

Future Efforts

Currently, the PGC Outreach Committee is volunteer-led with limited funding support. However, as our group and reach expands, we may seek funding opportunities to support our work. Future efforts from the PGC Outreach Committee will focus on expanding the PGC's public engagement by collaborating with science communication and journalism professionals to translate complex findings into accessible, compelling narratives, and continuing to focus on bi-directional communication with the public. A key initiative is the ongoing development of the Instagram account (@pgcgenetics), which aims to support real-time engagement with the public and help demystify psychiatric genetics, providing a range of content including "*What does heritability mean?*" and "*Can we genetically test for a psychiatric disorder?*". The PGC Outreach Committee will also review how it supports PGC members' outreach activities, taking direction from the WCPG 2024 outreach questionnaire, which highlighted the need for shared resources, workshops, web-toolkits and templates as practical ways to encourage outreach. Additionally, to promote and enable outreach across the range of scientific disciplines involved in psychiatric genetics, development continues on the PGC video textbook, which will feature science communication modules that detail how to tailor content and outreach strategies. Engagement with policymakers is outside the current scope of the PGC Outreach Committee, owing to the major differences in policymaking across the many nations from which PGC researchers come, so we have not addressed it in this paper. However, the 'PGC toolkit for strategic outreach' could be adapted by others and used as a starting point to bridge science and policy (e.g., funding priorities, ethical guidelines for genetic testing, and data sharing regulations), taking into consideration the complex systems of policy making that differ across nations and encompass factors such as the economy, the social environment, public health, and commercial regulation, to name a few (National Academies of Sciences, Engineering, and Medicine et al., 2017). Finally, incorporating the perspectives of those with lived experience of mental health conditions on science communication strategies will help ensure that messages are relevant, respectful, and resonate with the intended audiences.

Challenges

Ongoing challenges in outreach include the uneven regulation of and access to the internet and social media across countries—some lack access to major platforms, while others impose strict controls on content. Furthermore, the creation of engagement materials that effectively translate across cultural and linguistic boundaries presents a challenge for global outreach efforts. Meanwhile, the rapid pace of online content creation and dissemination continues to outstrip the development of consistent guidelines for responsible science communication. This makes strategic, thoughtful engagement in digital spaces increasingly vital for the psychiatric genetics community. Whilst increasing importance is being placed on outreach by universities and funders, the academic culture of "publish or perish"—which often prioritizes publications and citations over other activities such as public engagement—has not entirely dissipated, meaning researchers feel they must choose between career advancement and participating in meaningful outreach (Fracchiolla 2023). This tension, often referred to as the "researcher's dilemma", is exacerbated by the limited recognition of outreach in university and research settings and therefore the lack of time and resources set aside for outreach efforts, ultimately hindering both motivation and quality (Kassab 2019). Coupled with a lack of training opportunities and resources, this has led to uneven participation in outreach. The formation of the PGC Outreach Committee marks a significant and intentional step by the psychiatric genomics community to address these obstacles and prioritize public engagement as a core component of our mission.

Conclusion

The growing recognition of outreach as a complex and essential component of psychiatric genomics signals a positive shift in research culture. Several funding bodies, including the Wellcome Trust, have recently required engagement strategies in grant calls, while others, such as the European Research Council (ERC), strongly encourage this approach. The PGC is committed to expanding its outreach effort and impact through innovative digital tools, media partnerships, and enhanced bi-directional dialogue with community and support groups to co-create new research projects. Overall, these efforts will help ensure that psychiatric genetic discoveries are not only accurately disseminated but also ethically applied to drive progress in mental health care and improve outcomes on a global scale.

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Data Availability Raw data for the questionnaire results depicted in Box 1 are not publicly available to preserve individuals' privacy under the European General Data Protection Regulation. Aggregate-level data are provided in the Supplementary Materials.

Declarations

Competing Interests HLD, NMR, KKR, NB, JGM, RM, ARTK, OAU, ETCV, ECS, JMKY, MMW, MK, TS, AB, CML, JG, HJE have nothing to disclose. CM Bulik reports: Pearson Education Inc. (author, royalty recipient) and Orbimed (consultant). DM Dick reports: Danielle Dick is a Co-founder and Chief Scientific Officer for Thrive Genetics, Inc. She is on the Advisory Board for the Seek Women's Health Company. She has received royalties from Penguin Random House for her book, The Child Code: Understanding Your Child's Unique Nature for Happier, More Effective Parenting.

Ethical Approval The questionnaire in this study was designed by members of the PGC Outreach Committee and approved by the International Society of Psychiatric Genetics (ISPG). It was submitted to the Research Ethics Board (IRB) at University of North Carolina (UNC) at Chapel Hill and approved September 2024 (IRB #24–2076, Study Title: Evaluating Attendees Attitudes towards PPI [Public & Patient Involvement]).

Consent to Participate Informed consent was obtained from all individual participants included in the study.

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