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FoGS provides a public FAQ repository for social and behavioral genomic discoveries

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Abstract

Here we introduce 'FAQs on Genomic Studies' (FoGS), an open-access repository of explanatory documents that accompany genomic analyses in social and behavioral genomics. For fields such as social and behavioral genomics that are shaped by an ugly history and uncertain future, socially and ethically responsible research and research communication are crucial. FoGS amplifies one such approach towards responsible research communication.

Over the past two decades, rapid advances in human genomics have created new opportunities to incorporate molecular genetic variables into studies of social, economic and health outcomes. Such studies have shown that genetic variation can account for substantial portions of variation in a wide range of traits. These findings have, in turn, generated interest in genomic tools as a means to understand behavior and enhance efficiency and equality in the allocation of societal resources[1]. At the same time, studies into the genetic underpinnings of human behavior have been used to justify racist and eugenic ideologies. Arguments that appeal to genetic findings have consistently been used to create myths about immutable, biological differences between racial and socioeconomic groups, which result in unethical and discriminatory practices, such as the involuntary sterilization of the 'feeble-minded' (https://www.law.cornell.edu/supremecourt/text/274/200) and laws that outlaw interracial marriage[2]. To facilitate genetic literacy and avoid repeating this ugly

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Author contributions

D.O.M. and L.J.M. conceived and designed the repository overall. D.O.M., L.J.M., S.T. and B.W.D. all assisted with populating the repository, and D.O.M. and L.J.M. gathered permissions from authors for entry into the repository. D.O.M. and S.T. performed data analyses and contributed to data interpretation for the manuscript. D.O.M. wrote the manuscript with input from all co-authors.

Competing interests

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history, the proliferation of research into the genomic correlates of social outcomes should be accompanied by efforts to communicate research findings to general audiences in an ethically and socially responsible way such that potential harms are minimized and potential benefits to individuals and societies are maximized.

To that end, we introduce FoGS—an open-access repository (https://www.thehastingscenter.org/genomics-research-index/) that aggregates and enhances the accessibility of materials produced by researchers in social and behavioral genomics. FoGS is intended to host public-facing communications that offer accessible information on and context for recent findings in social and behavioral genomics. This repository comprises frequently asked questions (FAQs): explanatory documents that are designed to prevent misconceptions and misapplications and provide the context, scope and limitations of genomics studies. Given the increasing debate on the utility and applicability of social and behavioral genomics and the field's fraught history, we think that the launch of FoGS is appropriate and timely.

Although FAQs enhance the accessibility of genomics research, they usually exist in isolation from one another—posted on research consortia websites (https://www.sociogenome.org), personal websites (https://medium.com/@kph3k/investigating-the-genetic-architecture-of-non-cognitive-skills-using-gwas-by-subtraction-b8743773ce44), or occasionally even included in the supplementary materials of peer-reviewed research publications[3]. Before FoGS, the diffuse spread of FAQs made them difficult to locate. This was a disservice not only to the researchers who invested time and energy into producing these materials, but also to the many audiences who stand to benefit from this wealth of information. In an effort to amplify scientists' efforts to conduct ethically and socially responsible research communication and highlight best practices in FAQ construction, FoGS centralizes existing FAQs, and also provides brief, accessible explanations of each study (Fig. 1a).

At present, the scientific enterprise does not provide incentives for researchers to engage in the laborious process of creating FAQs on genomics studies; for example, they are not required for journal publication and are unlikely to be considered by tenure committees. We argue that any wide-scale adoption of initiatives such as the creation of FAQs will require structural change to the scientific research and publication enterprise, and increased recognition that research—much like the genome—does not operate in a vacuum[4]. Despite the lack of institutional incentives, researchers are increasingly recognizing the value of improving the accessibility of findings and proactively tempering claims about the potential implications of their research. At present, FoGS contains 19 sets of FAQs, but we anticipate that its existence will promote the utilization of this form of communication over time. Although the earliest FAQ in FoGS was published alongside a 2013 genome-wide association study (GWAS) on educational attainment[5], most FAQs (n = 13) were published after 2017, with almost half of those published in 2020 alone (Fig. 1b). The growing number of FAQ releases speaks to the burgeoning interest in incorporating FAQs into the publication process.

Origins of GWAS FAQs

Between 2011 and 2013, principal members and advisors of the Social Science Genetic Association Consortium (SSGAC)—an international research network of social scientists, geneticists and medical researchers interested in GWAS on social science outcomes—began to think about how to ensure responsible media coverage of GWAS (https://www.thessgac.org). The outcome of their deliberations was the development and distribution of FAQs about their papers to help journalists to avoid misinterpreting and misreporting social and behavioral genomic studies. Since the SSGAC's first FAQ in 2013, a growing number of research teams are adopting this mechanism for public communication to explain findings in specific genomic studies (Supplementary Note).

FoGS repository organization

FoGS comprises five sections that span GWAS and polygenic score (PGS) analyses: (1) educational traits and outcomes ($n = 6$); (2) social and environmental factors ($n = 3$); (3) psychological and psychiatric behaviors ($n = 5$); (4) sexual and reproductive behaviors ($n = 2$); and (5) miscellaneous ($n = 3$). Almost all of the FAQs (16) work to clearly explain an individual study in social and behavioral genomics. The remaining three entries include an FAQ on screening human embryos for polygenic traits using PGS, an FAQ on a pan-ancestry genetic analysis of the UK Biobank, and an FAQ on a scientometric review of 3,639 GWAS from 2005 to 2018. The single largest section of this repository comprises genomic studies that investigate traits and outcomes relevant to education ($n = 6$).

Each entry in FoGS links to the original study and FAQ, and provides a brief explanation of what the study examined and key findings. Entries also include the date of publication, name and contact information of the corresponding author, and any accompanying links (Fig. 1a and Supplementary Note).

The FAQs included in FoGS were sourced by a two-pronged method of web-based literature review and crowd-sourcing initiatives via email and social media. Journals were approached when necessary to gain permissions. This repository should not be considered an exhaustive list of available FAQs on social and behavioral genomic studies; FoGS is a living repository that is updated quarterly. In accordance with our submission guidelines (https://www.thehastingscenter.org/faqs-on-human-genomic-studies-submission-guidelines/?_thumbnail_id=26806), future authors can submit FAQs by emailing genomicsfaq@thehastingscenter.org (Supplementary Note).

Common themes

To communicate findings, implications and potential applications, FAQs work to create a baseline understanding of genomics research. For instance, several FAQs offer accessible explanations of GWAS and PGS, and ask and answer questions such as: "Did you find 'the gene' for educational attainment?" with "No. We did not find 'the gene' for educational attainment, cognitive function—or anything else" (https://www.thehastingscenter.org/wp-content/uploads/FAQ_EA1.pdf).

In addition, in an attempt to meet key considerations related to the responsible conduct of research, including maintaining integrity in science and discouraging unethical conduct (https://www.nih.gov/health-information/nih-clinical-research-trials-you/guiding-principles-ethical-research) these FAQs introduce the research team and their respective contributions and outline the goals of the research, main findings, and, in some instances, potential policy implications. These FAQs also highlight important interpretational caveats and methodological limitations of GWAS and PGS analyses, such as the limited capacity for polygenic scores to predict individual outcomes[6]. The pieces included in this repository also emphasize that genes are not immutable and deterministic 'fortune-tellers' and that genetic ancestry is not synonymous with the social construct of race.

Recommendations

FoGS aims to enhance responsible communication of social and behavioral genomics findings and the development of FAQs by providing access to exemplars of previous work. We hope that future FAQs will further the goal of responsible research by better outlining the facets of our social fabric that make research in social and behavioral genomics delicate. This may include: (1) acknowledging that genetic ancestry categories (for example, European, East Asian and West African) are socially informed; (2) defining the genetic ancestral categories used in a given study and explaining how they were created; and (3) probing the robustness of different quantitative genetic ancestry thresholds (for example, Figure S5 in ref.[7]).

We believe that future FAQs will probably be improved by including greater discussion of (1) specific research or policy applications that researchers consider (in)appropriate; (2) potential misuses or misapplications of the study's findings; and (3) explanations for why such applications would be improper. As an example of how an FAQ might discuss (in)appropriate policy applications, the authors of a 2020 FAQ on 'Investigating the Genetic Architecture of Non-Cognitive Skills Using GWAS-by-Subtraction', answered the question: "Are there any policy implications for this research?" with: "As more research like this study is conducted, and researchers know more about how to predict people's behaviors and life outcomes from their DNA (even when those predictions are made with uncertainty), the number of potential commercial, health, reproductive, and forensic applications multiplies. The potential number of policy implications increases accordingly, and some of these implications might be difficult to foresee…Generally, we think it will be important to remain vigilant against the possibility that genetic data will be used in ways that introduce or exacerbate inequalities in the distribution of freedoms, resources, or welfare. Additionally, we as scientists hope to contribute to discussions about how this research can be used to illuminate sources of injustice and to maximize the unique potential of each child" (https://kph3k.medium.com/investigating-the-genetic-architecture-of-non-cognitive-skills-using-gwas-by-subtraction-b8743773ce44).

In a discussion on potential misuses or misapplications, forthcoming FAQs might further promote social responsibility by discussing real-world developments such as the rise of for-profit, direct-to-consumer genetic testing and in vitro fertilization (IVF) companies that

are interested in using polygenic scores. It is our view that highlighting the methodological challenges and scientific unknowns that, for instance, limit the clinical validity of applying current polygenic analyses to IVF, are crucial responses to a rapidly growing marketplace of genomics-informed products and services that may be driven by profit more than by scientific reality.

Clear and responsible communication on the potential (mis)applications or implications of social and behavioral genomics requires acknowledging the social context in which research is produced and is necessary for minimizing the threats of misappropriation[8]. To assist with this aim, a template for producing FAQs is forthcoming. Generated in collaboration with previous FAQ authors, and a systematic review of all existing FAQs, the proposed template will address general points that will help to clarify and characterize the findings of any future social or behavioral genomic study. There are many ways in which researchers can clearly and responsibly communicate their research findings—our intention is to amplify FAQs as one important yet under recognized opportunity for public-facing communication. In addition, while we intend FoGS and a forthcoming FAQ template to increase the ease and accessibility of FAQ publications on social and behavioral genomics studies, the scientific community must remain vigilant to prevent these materials from becoming a simple box-ticking exercise. We think that the motivations behind these FAQs should overcome the lack of incentives for their creation within the research enterprise. As FAQs continue to appear alongside studies in social and behavioral genomics, it will be important to keep sight of the intended goals that led to their development.

Finally, just and equitable science should maximize the benefits and minimize the harms for individuals and communities most likely to be affected by research abuses in the future and those most harmed by unjust and inequitable research in the past. Importantly, our recommendations for enacting just and equitable science should not be considered specific to social and behavioral genomics; they apply to scientific research more broadly. However, we believe that social and behavioral genomics, given its the field's ugly history, will especially benefit from: (1) including colleagues from different disciplines with different perspectives on the risks and potential benefits of social and behavioral genomics (for example, through the process of adversarial collaboration[9]); and (2) engaging communities that are objects of study but whose voices often go unheard. The inclusion of stakeholders with unique lived experiences and viewpoints, especially in the decision-making process, may surface new approaches to addressing historical wrongs and preventing future abuses.

This article is a byproduct of adversarial collaboration. Its authors—researchers working in social and behavioral genomics and bioethics—came together to leverage our disagreements on the risks and potential benefits of genomics into a dialog; the idea for FoGS came out of these conversations. While we continue to have diverse opinions on key issues, we are united in our aim for this resource: to inform a broader audience and amplify socially responsible, commendable exemplars of science communication.

Reflecting on and expanding who we include in the scientific community will not only support the aims of just and equitable science, it will enhance our ability to ethically and responsibly communicate findings and open new avenues for inquiry and understanding. For

example, consider Indigenous researchers' push to improve Indigenous access to genetic and genomic research and healthcare;[10] such efforts have included holding researchers and funding agencies accountable to Indigenous research participants and their governing bodies and building Indigenous student, researcher and community capacity in ways that position Indigenous peoples are partners and leaders in genetic and genomic research (for example, https://nativebio.org/).

Conclusion

Social and ethical responsibility is an important component of the responsible conduct of genetics research, but difficult to enact in practice. Researchers find themselves navigating an ideological minefield in which some deny that genetic science might afford any benefits[11] and others overstate its importance and misappropriate it[8]. In short, the gene remains 'a powerful icon in the public imagination'[12], and social and behavioral genomics are unlikely to separate themselves from their ugly history. For this reason, the obligations of researchers to social and ethical responsibility in the field are and will remain important and challenging to fulfill. It is our hope that FoGS, our open-access repository of FAQs on human genomic research, sparks dialog on how best to achieve ethically and socially responsible research communication and provides easily accessible information for funders, researchers, policymakers, journalists, industry and patient groups on emerging studies in social and behavioral genomics.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Harden KP & Koellinger PD Nat. Hum. Behav 10.1038/s41562-020-0862-5 (2020).
2. Pascoe P What Comes Naturally: Miscegenation Law and the Making of Race in America (Oxford Univ. Press, 2009).
3. Hill WD et al. Nat. Commun 10, 5741 (2019). [PubMed: 31844048]
4. Martschenko DO & Smith M Nat. Genet 53, 255–256 (2021). [PubMed: 33686261]
5. Rietveld CA et al. Science 340, 1467–1471 (2013). [PubMed: 23722424]
6. Marigorta UM, Rodríguez JA, Gibson G & Navarro A Trends Genet. 34, 504–517 (2018). [PubMed: 29716745]
7. Domingue BW et al. Proc. Natl Acad. Sci. USA 115, 702–707 (2018). [PubMed: 29317533]
8. Panofsky A, Dasgupta K & Iturriaga N Am. J. Phys. Anthropol 10.1002/ajpa.24150 (2020).
9. Martschenko D, Trejo S & Domingue BW AERA Open 5, 1–15 (2019).
10. Garrison NA et al. Annu. Rev. Genomics Hum. Genet 20, 495–517 (2019). [PubMed: 30892943]
11. Witkowski J Nature 454, 577–579 (2008).
12. Lee SS-J et al. Genome Biol. 9, 1–4 (2008).
13. Warrier V & Baron-Cohen S Mol. Psychiatry 26, 1670–1684 (2021). [PubMed: 31659270]

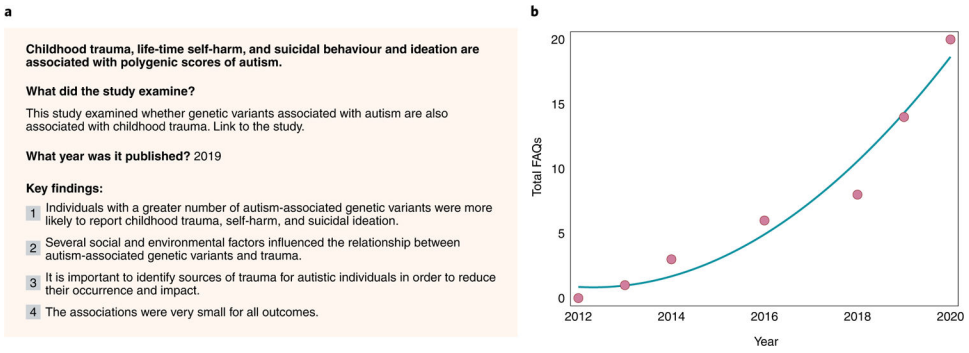

Fig. 1 |. Sample FoGS entry and the rise in FAQ publications over time.

a, A sample entry in FoGS of Warrier and baron-Cohen (2021)[13]. **b**, Scatterplot of the cumulative number of FAQs identified for inclusion in FoGS over time overlaid with a quadratic fit.