Published in final edited form as:

Disabil Health J. 2021 January ; 14(1): 100945. doi:10.1016/j.dhjo.2020.100945.

Hashtag who's missing? Lessons for genomic databases

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Abstract

Genomic databases support research intended to advance understanding, diagnosis, and treatment of disease. Utility is linked to diversity, and initiatives are seeking to enroll traditionally underrepresented groups such as people with disabilities. Commentators have called for adoption of a participant-centric approach to build trust and address barriers to inclusion. Complexities emerge, however, when minors are enrolled and whose perspective on their condition may with time diverge from their parents' perspective. Public response to MSSNG, a genomic database focused on autism, and public discourse regarding neurodiversity reveal division regarding autism as a difference or identity versus a disease. We explore what it means for genomic databases enrolling individuals, particularly minors, with disabilities to be participant-centric when affected individuals disagree about the nature of their condition and research priorities, offering recommendations for participant engagement and measures when enrolling minors with conditions that are the subject of difference-disease debates.

Keywords

Autism; Genomic databases; Precision medicine; Participant engagement; Neurodiversity

Genomic databases provide data access for research purposes, including supporting advances in understanding, diagnosing, and treating disease. A factor affecting the utility of data resources in translating data into knowledge is the diversity–or lack of diversity–of the people whom the data represent.[1,2] Initiatives such as All of Us are striving to enroll individuals representing various racial/ethnic and health profiles, including people with disabilities. All of Us has partnered with the American Association on Health and Disability, which stated: "For the first time, people with disabilities are being encouraged to participate and are being asked to enroll in a study that can directly impact how health care is received in the future. If we truly believe in the concept of 'nothing about us without us,' then we must answer the call when asked to participate."[3] A challenge with disability, as with race/ethnicity, is overcoming distrust related to previous abuse and exclusion by researchers.[4] Importantly, to the extent precision medicine initiatives invest in engagement and capture social and environmental as well as genetic variables, they have the potential to avoid misunderstandings and support development of research reflecting the priorities

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Submission declaration
A preliminary analysis of some of the data was presented at ELSI Congress 2017.

of those affected.[4] Therefore, achieving “participant-centric” data resources is important in building trust.[5]

Another important aspect of many data resources is the inclusion of (or in the case of All of Us, intention to include) minors. Longitudinal studies facilitate understanding of disease onset and its progression, and they will often involve following individuals from childhood. For example, many neurodevelopmental conditions, such as autism, are life-long chronic conditions that manifest in childhood.[6] Consent or permission for a child’s participation in research is typically granted by both parents or a legal guardian. In the U.S., children, with the exception of minors who meet certain criteria, cannot consent to research participation. Institutional review boards determine whether the child’s assent is also required.[7] Condition-specific pediatric research databases typically also enroll the biological parents of the affected child, and may include unaffected siblings, in order to examine potential causal genetic factors. Previous scholarly work exploring ethical concepts and best practices for enrolling minors in genomic databases focuses on the tension between protection against harm and inclusion as a basis for ensuring children share in the benefits of research.[8]

One ongoing ethical controversy is whether individuals enrolled by their parents in research biobanks or databases during childhood should be reconsented for continued participation at the age of majority.[9,10] In arguing against necessary reconsent, Benjamin Berkman and colleagues entertain the possibility of individuals developing values or an understanding of their interests at odds with continued participation. They conclude that “[d]onors with significant personal concerns *could* be permitted to request the withdrawal of their samples when they become adults; they just needn’t be asked for consent or assiduously tracked [emphasis added].”[10] This controversy may be especially consequential for research data resources enrolling minors with disabilities who may develop a perspective on their condition that is different from and even at odds with the perspective that motivated their parents’ enrollment decisions.

To explore how genomic databases enrolling minors and intended to facilitate research may be perceived by some as indifferent or even antithetical to the needs and interests of those whom the data describe, we explore the controversy around the launch of MSSNG, an autism spectrum disorder (ASD) genomic database. Conversations regarding MSSNG on Twitter raised important issues related to the creation and use of data resources for biomedical research and the engagement of individuals affected by the condition being researched. These conversations frequently referenced *#NotMssng*, a counter-hashtag used to express discontent with MSSNG and to claim autism as a difference and in some cases a positive identity, rather than a disorder or disease. While we recognize that the autism community is not representative of all persons with a disability or condition-specific communities, the availability of public comments on MSSNG offers an opportunity to capture critical responses and suggest some general lessons for sponsors and developers (“planners”) of data resources. We then shift to the current polarization within the autism community to glean additional insights to inform a set of recommendations for data resources enrolling minors and supporting research on conditions that are the subject of difference-disease debates.

The MSSNG controversy

MSSNG launch

MSSNG is sponsored by Autism Speaks, a non-profit organization, in collaboration with Google, Sick Children's Hospital in Toronto, and DNAStack.[11] The project aimed to sequence 10,000 biosamples from people, including children, stored in the Autism Genetic Research Exchange, a biorepository managed by Autism Speaks, and additional sources.[12,13] The project changed its name to *MSSNG*, as the planners believed the two omitted I's represent the missing information about ASD.[14] MSSNG data are made available to approved researchers. On December 9, 2014, MSSNG was announced.[15] That same day, the hashtag #NotMssng emerged on Twitter.

Backlash on Twitter

We reviewed 442 Tweets linked to #NotMssng posted on December 9, 2014 by 201 unique users. Using NVivo 11 Pro, we classified users based on their connection to autism, if expressed, and coded Tweets following a thematic content analysis approach to derive the themes in Table 1. Overall, 112 (56%) users self-identified as having autism and 20 (10%) mentioned knowing someone with autism. Many individuals posting with the hashtag *#NotMssng* interpreted "MSSNG" to mean that *they*, the autistic individual or autistics collectively, were missing or are missing something. They rejected the message of a deficiency and called for the inclusion of autistic voices missing from the conversation. In addition, many felt that support and services for autistic individuals are lacking and should be the focus of research. In regards to the perceived research priorities of the MSSNG sponsors, many interpreted the purpose of finding a cure as an attempt to eliminate people with autism. Finally, several users implicitly rejected "people first" language, intended to emphasize the person rather than the disability, labeling themselves as autistic or autistics rather than persons with or having autism. In doing so, they underlined the importance of autism to their identity. Of note, while some herald Autism Speaks as an advocacy group doing important work on behalf of people with autism, it has been criticized by others as an organization that was not created by and has not been led by people with autism themselves (as suggested by comments in Table 1 #NotMssng Tweets indicating that Autism Speaks does not speak for or listen to autistic people).

Context: A polarized community

Although #NotMssng documents rejection of MSSNG and related research efforts, the ASD community is divided on whether research seeking a cure or treatments for autism is desirable. On Twitter, the #AutisticDarkWeb thread illustrates opposition to the neurodiversity perspective. Compared to #NotMssng, this hashtag garnered less traction with 198 Tweets captured in the month of its launch (June 2018) by 48 users. Five (10%) expressed being autistic and four (8%) know someone with autism. In reference to #AutisticDarkWeb, a blogger wrote: "… there are more of them [neurodiversity activists] active online and in govt [government] lobbying than there are of us, so we're outgunned. I realize there are others and I'm not alone, but it's still an uphill battle and a bit discouraging."[15] Also a Facebook survey conducted and reported by a blogger with autism included individuals with ASD (n = 3,431) and without ASD (n = 5,751). The majority of respondents with ASD (n = 2,471, 72%) would reject a cure for autism, whereas respondents without ASD were divided. Stratifying the sample of respondents with autism by nature of disability, the majority of those who self-reported being nonverbal/selective mute and/or experiencing learning challenges rejected a cure.[16]

Moreover, an April 2019 article published on *Spectrum*, an e-news website funded by the Simons Foundation Autism Research Initiative,[17] describes the “autism wars” as a tension between people who view ASD from a neurodiversity perspective and do not want a cure (like many #NotMssng contributors) and people who view ASD as a pathology in need of a cure. The author suggests that diagnostic criteria may be contributing to the tension: “Over the past two decades, as the spectrum has broadened to include those with milder traits, this fight has flared into an all-out war that plays out on social media, on the internet and at community meetings.”[18] In addition, and arguably, the people with autism posting comments on the Internet, whether in favor or against a cure, do not represent the perspective of those with more severe traits and unable to communicate through a computer. These caveats should be considered, but they do not nullify the value of the perspectives from affected individuals expressed publicly on Twitter and elsewhere as sources of insight.

Researcher Simon Baron-Cohen is notable for seeking a middle way. In a 2017 editorial, he supported separating autism from comorbidities such as epilepsy and stated that the appropriate response to autism-as-disability is “societal support, acceptance of difference and diversity, and societal ‘reasonable adjustment,’” while also stating that parents “deserve the freedom of choice” to try interventions.[19] His 2019 blog post concludes that the neurodiversity and medical perspectives can be integrated via an acknowledgement that “autism contains huge heterogeneity.”[20] However, harmony has not yet been achieved. Two responding commentaries offer opposing views, with one finding mistakes in Baron-Cohen’s description of the neurodiversity movement and harm when therapies seek to reshape an autistic child’s behavior,[21] and the other rejecting the separation of co-morbidities, describing the outlook for affected individuals as bleak, and supporting more research into causes.[22]

Recent developments

Today, MSSNG remains active, and on May 2019 achieved its goal of sequencing 10,000 individuals.[11] In a noteworthy change, possibly unrelated to #NotMssng but relevant to this discussion, Autism Speaks removed the word *cure* from its mission statement in 2016. In announcing the change, Autism Speaks stated that they seek “research advancements that improve the quality of life for autistic people today and appropriate personalized treatments in the future.”[23] Autism Speaks is not alone in the autism biomedical research space. Another organization offering a data resource is the Simons Foundation, which funds the Simons Simplex Collection (SSC), a repository of genetic data of families with an autistic child.[24] General, broad databases may also be used to support research on ASD. For example, as of April 19, 2020, twenty-four projects related to autism received access to the UK Biobank database.[25] Thus, the MSSNG backlash and the polarization within the autism community matter for both condition-specific and broad genomic data resources.

Discussion

According to sociologist Jennifer Singh, strides in autism genomics research and data sharing can be ascribed to efforts from parental advocacy and the research community.[26] Singh interviewed parents to understand their motivations for enrolling their child in the SSC. She found that parents were driven by desires to help future families, avoid feeling guilty by doing everything possible to help their child, and obtain free clinical diagnosis to qualify for early intervention and educational services.[27] These motives center on the parent's desire to provide for their child. However, the consequences for the child, and the perspective the child might adopt toward autism and autism research as he or she matures, did not appear to enter into the parents' decision-making. Parents are entrusted to make decisions based on what they believe is best for the child.[8] Access to services generally serves the child's interests, but it may be necessary to prompt parents to consider the child's future attitudes towards being enrolled in a genomic database.

In general, where parents are enrolling minors with a condition regarded by a majority or significant minority of affected adults as an identity, not a disorder or disease, and the resource is intended to be available for research focused on cure (or developing treatments that would approximate eradication of the condition), planners have certain core responsibilities to participants. These include implementing measures such as notification of the option of withdrawal or reconsent when minor participants reach the age of majority. The violations and harms associated with having one's genetic material used without one's explicit consent for research to which one has fundamental moral objections are substantial. Tweaking Berkman and colleagues' language, when fundamental moral objections are known to exist within a group, and we anticipate some of those enrolled as minors will develop into adults who share those objections, then these donors-by-proxy *should*, at a minimum, be permitted to request withdrawal as adults. Recognizing an obligation on the part of planners to at least provide notice is less disruptive to the current paradigm than universal mandate of withdrawal unless there is reconsent, but it still represents a step beyond the wholly discretionary position espoused by Berkman and colleagues. Also, efforts should be made to track data in order to facilitate withdrawal, as well as to update contact information to support notice about the option of requesting withdrawal at the age of majority.

In line with a commitment to participant-centricity, engaging participants and earning their trust is a goal of many data resources. Distrust of data uses may deter people from participation or lead to withdrawal of data, affecting the sustainability and utility of a data resource. Often, participant engagement varies.[5] A formerly publicly available document indicated that MSSNG employed a representation-in-governance approach to participant engagement. A Data Access Compliance Office, whose membership is appointed by the Public Population Project in Genomics and Society and includes a member of the autism community, along with Autism Speaks and any collaborating organization, is responsible for the implementation of the MSSNG Data Sharing Policy and Procedures.[28] In other forms of engagement, community members help planners think through aspects of an initiative in relation to community concerns, which may include alerting planners to areas of sensitivity or potential misunderstandings.[29] The response on Twitter to the MSSNG project shows how the name “MSSNG” became a flashpoint. Perhaps the backlash would not have occurred under a different name. If so, then engaging affected individuals who represent different perspectives could help anticipate a community’s response to the research and better inform branding and strategies to communicate with the public.

People with autism or who self-identify as autistic are not alone in desiring research to diminish the challenges of daily living and change the environment, social structures, and public policies to better meet their needs and support their flourishing. Similar procure/anti-cure tension exists outside the autism community, affecting individuals who are Deaf or have Differences of Sex Development.[6] Planners should consider how data resources intended to support genetic research might be constructed to facilitate other kinds of research as well as policy development. Planners might also nudge (or push) users of the resource to demonstrate engagement in an effort to shape their research goals to community concerns. Central to achieving a participant-centric resource is engagement done comprehensively so that it elicits the views of leaders and also captures the perspectives of individuals “on the street.”[5]

When planning data resources, it is naïve to think that initiatives venturing into areas with tensions or disagreements described as “war” can please everyone. It may nonetheless be worthwhile to complement general community engagement with targeted outreach to those most likely oppose an initiative, not with a goal of convincing them, but with a goal of respectful listening to concerns.[5] Doing so can also help anticipate concerns from individuals enrolled by their parents as minors and plan for strategies to reconsent or withdraw data upon reaching the age of majority, if deemed appropriate by members of the community. Engaging newly-turned adults offers an especially important opportunity to gain relevant insights into how perspectives may evolve over time with increasing maturity and to understand what is required to respect the rights and interests of adults enrolled as minors by a surrogate decision maker. In short, there is a feedback loop between this recommendation and the recommendation concerning measures to show respect toward participants as they develop identities independent of their parents. While engagement might not be welcomed by all researchers, engagement is consistent with developing norms, and one academic journal already requires documentation of patient and public involvement.[30]

Although we cannot confirm the age of people posting based on the Tweets themselves, people posting using #NotMssng may include minors since Twitter users may be as young as 13 years old.[31] Another challenge with understanding the #NotMssng controversy is determining how representative the #NotMssng backlash is of the autism community. As Baron-Cohen stated: “‘We don’t know what proportion of the autism community is pro- or anti-neurodiversity,’ … ‘When you see criticism on Twitter, for example, you don’t know if it’s just a small number of individuals generating all the buzz about neurodiversity.’”[18] Furthermore, the validity of the Facebook survey findings is unknown, as that study was not peer-reviewed. However, findings from a UK study[32] with autistic adults are congruent with the sentiments expressed through #NotMssng and the Facebook survey. Exploring unconventional sources of data, such as Tweets, can provide an important perspective from a sample of people who may be unrepresented in academic literature, and help inform the basis for recommendations (see Table 2) to planners of focused and general data resources with relevance to conditions some regard as differences and potentially sources of identity.

Developing participant-centric data resources when divisions across and within participant and other stakeholder groups exist is challenging. Creating data resources that contain data from minors enrolled by their parents adds a layer of complexity, especially when the resource supports research on conditions implicated in difference-disease debates. However, creating representative and trusted data resources is important for sustainability. Social media platforms offer access to public discussions that capture the pulse of communities and potential dissenting opinions from those represented in the data. Engaging affected individuals who represent different perspectives, as well as surveying discourse on social media platforms, can inform messaging about the purposes of a data resource and help planners anticipate and address dissenting opinions (and conspiracy theories) that may erode trust from individuals, particularly among those enrolled as minors. The MSSNG controversy informs an initial set of recommendations, but ideally this Commentary will serve as a catalyst for wider reflection and further refinement of guidance.

Acknowledgments

Disclosure

The work presented was supported by the National Institutes of Health, National Human Genome Research Institute, grant R01HG008918. The opinions expressed are solely those of the authors, who declare no conflicts of interest.

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Table 1

Themes and examples of illustrative #NotMssng Tweets.

Theme	Corresponding Tweets
Internalization of autism as part of self-identity.	“I am Autistic and I am #NotMssng! I am right here and I can speak for myself”
Representation of a collective autistic identity.	“We are here, We are healthy, We are intelligent, We are #NotMssng. Please listen to us for once Autism Speaks instead of hurting us!”
MSSNG interpreted to mean autistic people are missing or are missing something.	“Disability is a natural part of the human condition. We are #NotMssng, we are not less than, & not #Mssng our humanity.”
Autistic people are missing from the conversation.	“How appropriate they chose the letter I. I am Autistic, but when Autism Speaks is involved, I am #mssng from the conversation. #NotMssng”
Support and services for autistic people are what is missing.	“I am not autistic, but the autistic people in my life are #NotMssng. What IS ‘mssng’ is support and respect for autistic people.”
	“How about research into supports and services instead of elimination and cure? #NotMssng #Mssng @autselfadvocacy”
Attempts to develop a cure for autism are equivalent to attempts to eliminate people with autism.	“@autismspeaks Autism has no cure because it is hard-wired in the brain. If you eradicate autism, you eradicate autistic people. #NotMssng”

We consulted with the Baylor College of Medicine Institutional Review Board (IRB), and the IRB confirmed that the use of Twitter data is exempt from human subject research oversight under 45 CFR 46.102(f) (under the version of the Common Rule that took effect July 19, 2018, 46.102(e)).

Table 2

Recommendations for planners of genomic databases.

1. **Take concerns especially seriously if enrolling children.**
   - Prompt parents to consider the child's future attitudes towards being enrolled in a genomic database.
   - Where identity-based concerns about research are common among affected adults, track data to facilitate withdrawal and provide notice of withdrawal option at age of majority.
2. **Incorporate community engagement representing diverse perspectives.**
   - Consider enlisting community members, particularly newly-turned-adults for pediatric databases, as advisors regarding areas of sensitivity or potential misunderstandings.
   - Engage affected individuals who represent different perspectives, and survey discourse on social media platforms, to build and retain trust and inform messaging about the purposes of the data resource.
   - Conduct targeted engagement of likely opponents with a goal of respectful listening, not conversion.
3. **Adopt a wide view of potential research goals.**
   - Consider constructing the database to facilitate multiple kinds of research to comprehensively address the needs/flourishing of those affected by included condition(s).