

# Constructing Citizenship: A Qualitative Content Analysis of the All of Us Research Program's Social Media Outreach

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## Introduction

Precision medicine is a nascent field that seeks to personalize medical diagnoses and treatment by incorporating factors like genetics, lifestyle, and environment. However, certain populations remain historically underrepresented from such research, threatening the exacerbation of pre-existing health disparities.<sup>1</sup>

First announced in 2015 as the "Precision Medicine Initiative," the All of Us Research Program (AoU) is a national precision medicine initiative that recognizes the ethical and scientific need to enhance diversity in biomedical research. In fact, AoU explicitly prioritizes the recruitment and retention of participants from underrepresented backgrounds. Of the 1 million participants whom AoU seeks to enroll, the program aims for 70% of these participants to be underrepresented in biomedical research.<sup>2</sup>

Similar to other initiatives, AoU collects biosamples and health, lifestyle, and environment data from participants for use in research. However, AoU announced on 12/10/21 that it would be among the first genomic data programs worldwide to return genetic results to participants at a massive scale.

To understand how AoU implements its goals for "diversity" and "inclusion" in practice, we examine the program's calls for participation, especially for underrepresented groups, in its social media messaging.

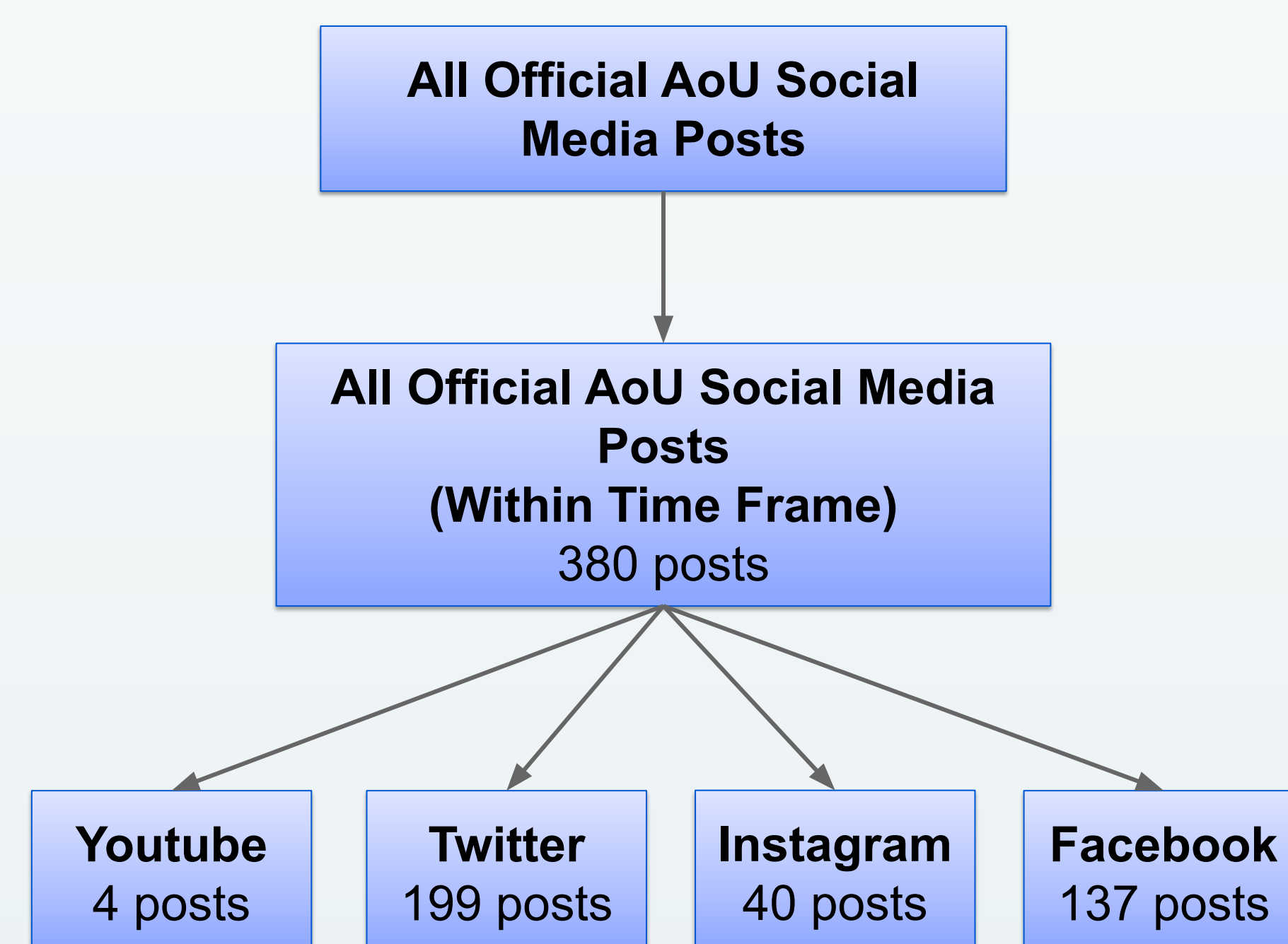
Through this case study, we build upon the rich literature surrounding biological, genetic, and genomic citizenship by exploring the "citizenship" constructed by AoU.<sup>3,4,5,6,7</sup>

## Research Questions

1. How does AoU invoke, draw on, and/or modify different notions of "citizenship," and how does it connect biomedical research to ideas about belonging, benefits, and obligations?
2. Which underrepresented categories and groups in biomedical research, as defined by AoU, are being targeted by their digital calls for participation, and which are being left out?
3. How can AoU shift the framing and audience of its social media outreach to towards shaping a more "inclusive" future of precision medicine research?

## Materials and Methods

The dataset of this study includes all official AoU social media posts published 3 months before and after 12/10/2021.



Using AoU groups/categories for underrepresented populations in biomedical research (see below), an individual coder sorted the data into each group/category.<sup>8</sup> This sorting was done when groups/categories were explicitly mentioned (in images or captions) or visually depicted (in images).

Category	Groups
Race and Ethnicity	Asian; Black, African, or African American; Hispanic, Spanish, or Latino; Native Hawaiian or Pacific Islander; Middle Eastern or North African; Other Race/Ethnicity
Access to Care	Not had a needed medical visit in the past 12 months; Cannot easily obtain or pay for medical care as needed
Age	Children < 17; Adults > 65
Annual Household Income	Household incomes < 200% of the Federal Poverty Level
Disability	Physical disability; Cognitive disability
Educational Attainment	Less than a high school degree or equivalent
Gender Identity	Gender variant; Non-binary; Transgender; Other gender
Geography	Rural and non-metropolitan residence
Sex Assigned at Birth	Intersex; Other sex
Sexual Orientation	Asexual; Bisexual; Gay or lesbian; Other orientation
Women*	-
Non-specific	-

Currently, we are conducting a qualitative content analysis (QCA) of AoU social media outreach to identify key themes embedded within AoU's messaging.<sup>9</sup> This process involves one coder open coding a subset of the entire dataset (with an individual post as the unit of analysis). An initial codebook of is generated, verified and revised by a second coder, and the revised codebook is used to code the entire dataset.

## Preliminary Results

Categorization of explicit and/or visual appeals to these groups elucidate overwhelming emphasis on racial/ethnic diversity in social media communications. The most frequent categories/groups are shown below.

Categories and Groups Invoked Most Frequently	Percentage of Dataset
Race and Ethnicity	49.9%
Black; African; or African American	30.4%
Hispanic; Spanish; or Latino	19.9%
Asian	8.1%
Age	18.6%
Children < 17	11.0%
Adults > 65	8.7%
Non-specific	5.2%
Women	4.2%

Categories Invoked Least Frequently	Percentage of Dataset
Gender Identity	0.8%
Sex Assigned at Birth	0.8%
Sexual Orientation	0.5%
Geography	0.3%
Annual Household Income	0%
Access to Care	0%
Disability	0%
Educational Attainment	0%

A subset of the codebook, specifically codes that correspond to possible benefits of participation, is displayed below.

Code	Definition	Example
Joining a large community	When the AoU's large research community is referenced.	"We're building a research community of 1 million participant partners"
Receiving individual results	When returned "results" are referenced explicitly.	"We're currently returning results to some All of Us participants who were invited to give samples"
Equitable benefit	When equitable benefit from research is referenced (e.g. the needs and outcomes of different groups).	"All of Us is committed to helping improve health equity"
Discovery power of data	When the discovery power of data is referenced.	"We're grateful for the ability to use our dataset to shed light on the spread + impact of COVID-19"
Drive research	When references to participation driving research (on health, disease, etc.) or "learning more" are made.	"As part of our program, you're helping to drive research forward"
Changing the future of health	When references to the future of health are made.	"You may help change the future of health for you, your family, and your community."
Research as hope	When research is framed as hope (e.g. for a better future, and as a solution to an urgent crisis like the pandemic).	"When it comes to finding answers about our health and learning new ways to stay healthy, research is hope"

## Future Plans

This study is still ongoing, but our preliminary results demonstrate several key categories and groups, among those specifically targeted as "underrepresented" in AoU recruitment, that are relatively over- and/or under-emphasized in current AoU social media outreach efforts.

One next step to our labeling of AoU's explicit and/or visual appeals to underrepresented groups/categories is having at least one other coder similarly label appeals to these groups to resolve any ambiguities.

Regarding the ongoing QCA, our next steps will be to assess intercoder reliability by having the same coder who generated the preliminary codebook and an additional coder both code the pilot dataset with said codebook. If intercoder reliability is too low, the codebook will be revised and the process repeated until reliability is sufficiently high.

Next, this codebook will be used to code the remaining two-thirds of the dataset. Using qualitative data analysis features found in Dedoose (a program designed for qualitative research), codes will be further re-organized based on similarities and differences across coded excerpts.

Finally, associations between different codes will be analyzed to elucidate possible patterns, and the occurrence rate of each code will be analyzed to quantify the prevalence of individual themes.

Altogether, this data on *who* is being appealed to and *how* they are being called to action through specific messaging will enable AoU to assess whether its current outreach strategy aligns with underlying diversity and inclusion goals. In the process, our case study will further develop, modify, and complicate contemporary notions of "citizenship" in the context of precision medicine research.

## References

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