



Who is Represented in the Nation's Biobanks?

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Introduction

As the science of genetics and genomics is developed, there is a risk of increasing health disparities for populations who are not adequately represented.¹

Purpose

1. To conduct a national survey to assess the rate of minority participation in research biobanks.
2. To describe and categorize the recruitment and enrollment procedures using the Suitability of Assessment guidelines³ and determine if they are linked to electronic medical records.

Methods

We identified 155 biobanks through internet searches and NIH RePORTER funded studies.

Inclusion criteria: samples be available to qualified investigators, and that the biobank would be expected to reflect demographics of the U.S.

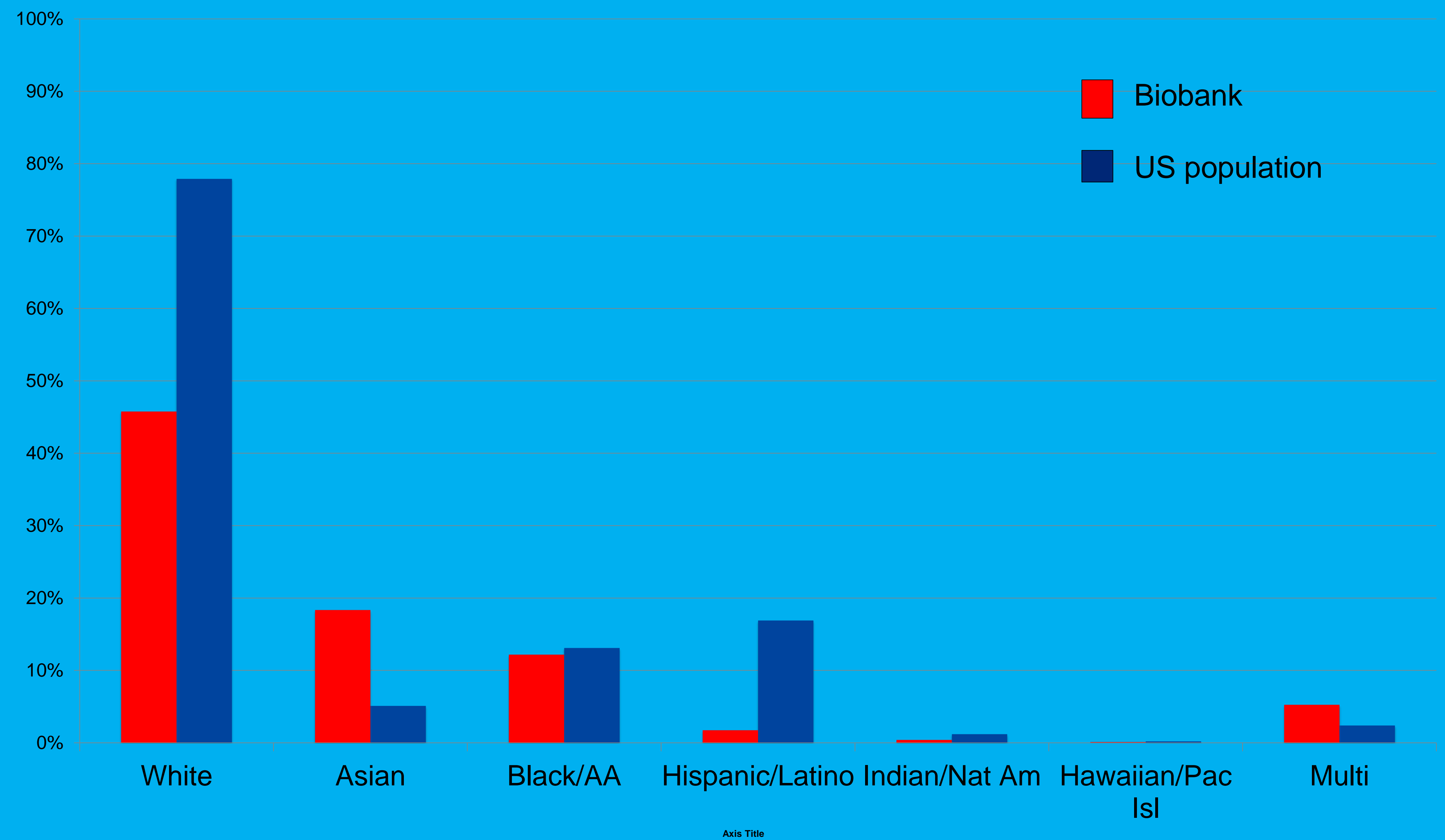
Excluded criteria: specialty biobanks or those open to researchers.

Dillman's² procedure for research was followed to survey biobanks from across the nation. United States census data was used for comparative population data.

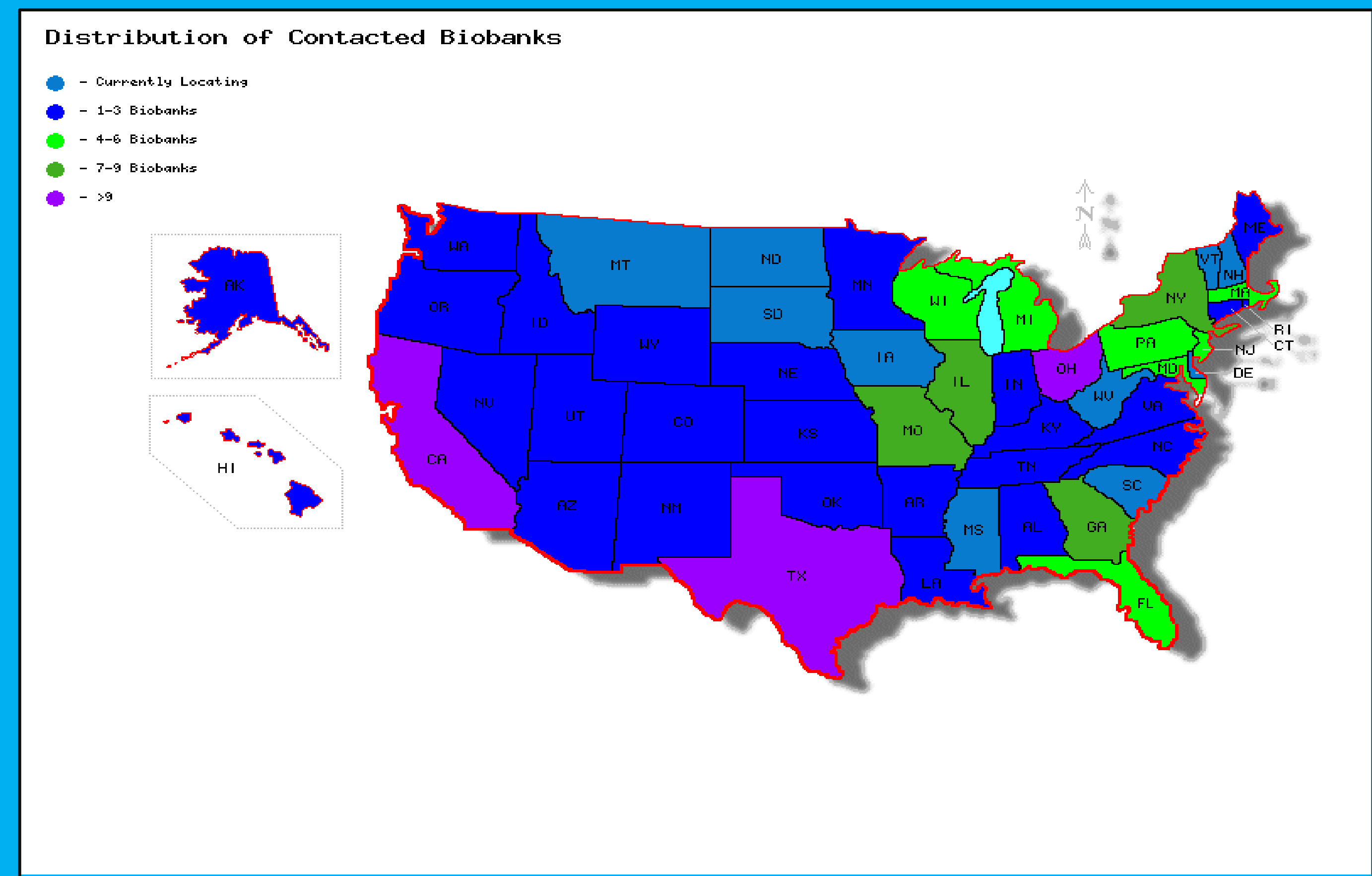
Results

To date, 61 biobanks have complete the survey providing information about the demographics, consent, recruitment and enrollment procedures of over 1,200,000 specimens.

US population demographics compared to those enrolled in biobanks by percentage (N=1,200,000)



Distribution of biobanks in this study



Conclusion

- Hispanics and Latinos are significantly under-represented in biobanks relative to their representation in the population.
- 70% of biobanks were not linked to electronic medical records.
- Recruitment materials and websites remain at reading levels too high for the general public.
- Recruitment materials lack pictures of diverse participants and were only available in English.

References

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