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ATTITUDES TOWARDS CENTRALIZED BIOREPOSITORIES AMONG PATIENTS IN CLEVELAND, OH: IMPLICATIONS FOR THE PRECISION MEDICINE INITIATIVE COHORT PROGRAM

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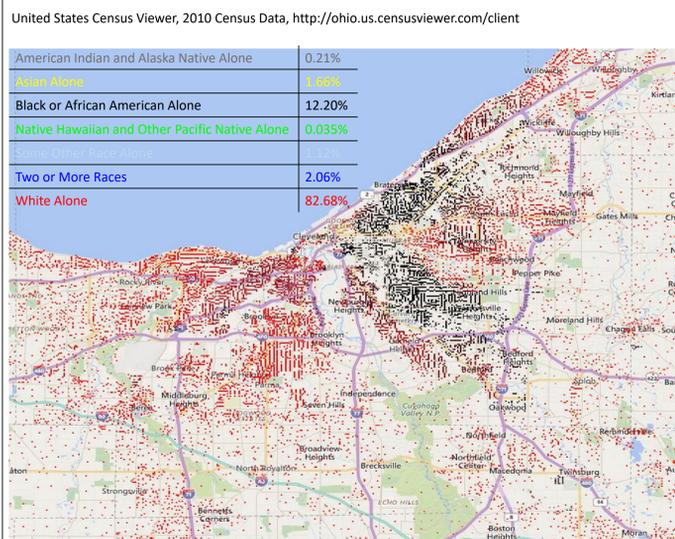
INTRODUCTION

The Precision Medicine Initiative, announced by the White House in early 2015, promises to revolutionize patient care by incorporating clinical, environmental, personal, and 'omics data in electronic health records (EHRs) for decision support at the point of clinical care. To accelerate this vision, the National of Institutes of Health in consultation with academic, healthcare, mHealth, and patient advocacy leaders, is launching the PMI Cohort Program (PMI-CP), an ambitious national effort to ascertain one million Americans for precision medicine research.

A requirement of this cohort is the submission of biospecimens, which will be sent to a central biobanking facility funded by the government for storage and further processing for data generation. While this centralized model of biobanking provides quality control and is cost-effective compared with a federated model, it is not clear what impact this requirement will have on ascertainment, which is expected to be diverse socio-economically, geographically, and racially.

To understand the potential impact this model has on ascertainment, we are surveying patients participating in a precision medicine research project at MetroHealth in collaboration with the Institute for Computational Biology at Case Western Reserve University in Cleveland, Ohio, a diverse metropolitan area with 20% of residents self-described as African American in the 2010 U.S. Census (**Figure 1**). MetroHealth is an academic, public provider, integrated tertiary care system serving Cleveland and northeast Ohio with a vendor-based (Care Everywhere, Epic Systems Corporation) electronic health record. Annually, the system has approximately one million outpatient visits, 100,000 emergency department visits, and 30,000 inpatient admissions, and the payer mix includes 21% uninsured, 24% Medicaid, 18% Medicare, and 37% commercial insurance.

Figure 1. Distribution of Race in and around Cleveland, Ohio.

United States Census Viewer, 2010 Census Data, http://ohio.us.censusviewer.com/client

American Indian and Alaska Native Alone	0.21%
Asian Alone	1.66%
Black or African American Alone	12.20%
Native Hawaiian and Other Pacific Native Alone	0.035%
Two or More Races	2.06%
White Alone	82.68%

METHODS

The goal of the MetroHealth – CWRU Institute for Computational Biology Pilot study (MIPs) is to link EHR data to biospecimens. The target sample size is 250 individuals. Eligible individuals were asked by their primary physician if they would consider participation, those who did completed formal in-person consent with a study coordinator and signed informed consent documents. All procedures and processes including the survey were reviewed and approved by the local institutional review board. Individuals who agreed to participate in the MIPs allowed a blood draw for genetic analyses.

The following survey was administered to participants to assess attitudes towards the PMI-CP in the diverse population sample that is served by MetroHealth.

1. Would you be willing to allow your health records and genetic information to be stored in a national biorepository coordinated by the government as a part of their "Precision Medicine Initiative"? If so this information may be available to researchers nationally and internationally with the understanding that your privacy would be protected.

____ Yes   ____ No

2. Would you be willing to install a free phone app that would be able to track your physical activity, measures of your health and location with the understanding that your privacy would be protected?

____ Yes   ____ No

3. Would you be willing to allow the information collected using the phone app (question 2) to be send to the national coordinating center where it may be shared with researchers nationally and internationally with the understanding that your privacy would be protected?

____ Yes   ____ No

4. If you participated in a study that collected your genetic and health information, how important is it to you that you receive results from the study? Circle the number that is closest to how you feel.

1 - 2 - 3 - 4 - 5

Not at all important   Somewhat important   Very important

5. What type of results would you like to receive, please check all that apply:

a. ____ Information about the average results of all participants and nothing about yourself specifically.

b. ____ Information about yourself that your doctor may have already provided to you (for example; smoking or excess weight), which may increase your risk for future health problems.

c. ____ Information about your genes that may influence your doctor's approach to your care (for example; they may order additional testing or consider alternative treatments or medications).

d. ____ Information about your genes that has uncertain significance and will not change the way that your doctor treats you.

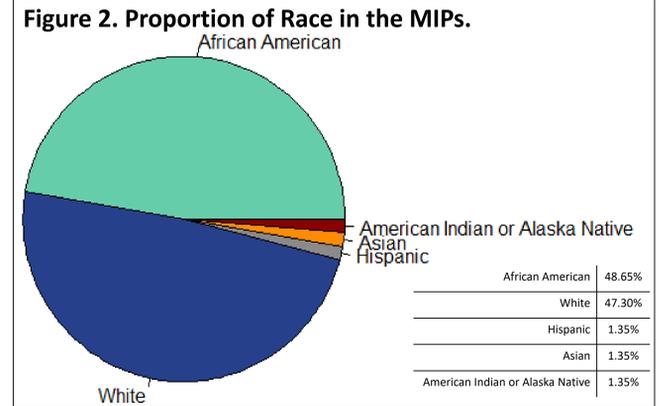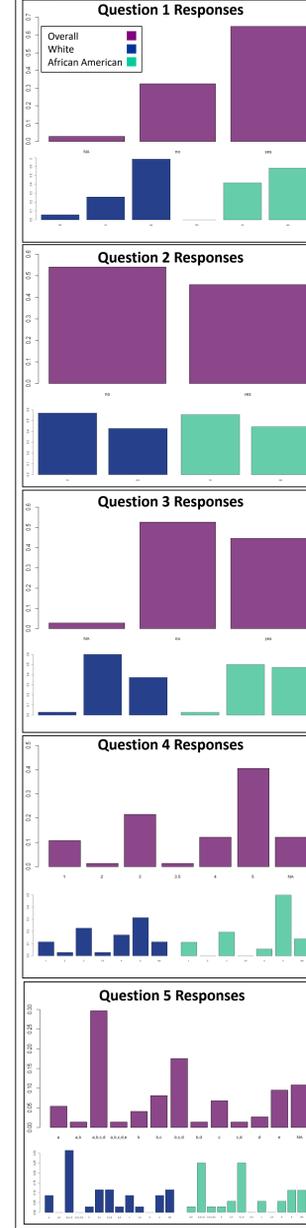e. ____ I do not want to receive any results.

RESULTS

Figure 2. Proportion of Race in the MIPs.

African American	48.65%
White	47.30%
Hispanic	1.35%
Asian	1.35%
American Indian or Alaska Native	1.35%

Figure 3. Survey Results.

MIPs
There are currently 83 participants in the MIPs.
o 58% Female
o Average age: 61 years

Survey Results
92% of MIPs participants completed at least part of the survey (results summarized in **Figure 3**).

PMI Participation
o More individuals were willing to participate in the PMI than not (Q1); however, individuals were less likely to install a phone app (Q2) and allow that app to track their personal data (Q3).

Return of results
o Responses widely varied regarding importance of return of results; the majority of individuals considered this very important (Q4).
o 11.8% of respondents did not want any information returned (Q5e).
o Of individuals who wanted results returned(Q5):
  • 58% at least summary data
  • 6.8% only summary data
  • 83% at least health data
  • 6.8% only health data
  • 85% at least genetic data
  • 10.2% only genetic data.
  • 93% at least self-data

Stratification by Race
(African American and White)
o No significant difference between group responses to Q1-4.

SUMMARY & FUTURE DIRECTIONS

These responses, while preliminary, indicate that the attitudes of patients in a diverse health care environment towards the PMI-CP are varied. In this small sample we have not detected a difference in participation responses when stratified by race.