**TORONTO**

STAFF REPORT
INFORMATION ONLY

# Socio-Demographic Data Collection Update

| Date: | July 31, 2014 |
|---|---|
| To: | Board of Health |
| From: | Medical Officer of Health |
| Wards: | All |
| Reference Number: | |

## SUMMARY

This report provides an update to the Board of Health (BOH) on the progress of Toronto Public Health's (TPH) collection of socio-demographic data, as directed by the BOH in November 2013. Specifically, this report provides information on a socio-demographic data collection tool that was piloted at TPH, the strategy for ongoing data collection, as well as consultations with key stakeholders including the City Manager on strategies to influence the broad-based collection of this type of data.

### Financial Impact
There are no financial implications.

## DECISION HISTORY
At its November 4, 2013 meeting, the BOH approved the *Racialization and Health Inequities in Toronto* report, which found that members of racialized groups experience poorer health outcomes compared to members of non-racialized groups, and that experiences of racial discrimination contribute to poor health outcomes. (http://app.toronto.ca/tmmis/viewAgendaItemHistory.do?item=2013.HL25.1)

## ISSUE BACKGROUND
The *Racialization and Health Inequities in Toronto* report contributed to the growing body of evidence that correlates the experience of racialization with poor health. However, the report could not provide a complete analysis of racialized health disparities because race-based data is not routinely collected in Canada. Where such data exists, each data set categorizes 'race' in its own way, rendering comparisons challenging. Producing the report underscored the larger issue of the lack of consistent and reliable socio-demographic data in Canada.

For several years now, TPH has been actively investigating the best methods for collecting client socio-demographic data and recently completed a multi-year pilot project that generated an evidenced-based data collection tool. This tool was adopted by the Toronto Central Location Health Integration Network (TCLHIN), and as a result, all eighteen of its hospitals and seventeen community health centres are implementing the data collection tool. Likewise, TPH has started the process of integrating the eight core socio-demographic indicators into the sixteen databases that support TPH's fifty-one public-facing programs. The data that TPH collects will be stripped of identifying information and the aggregate data analyzed for equity planning and service delivery purposes. In the future, TPH's data may be pooled with the TCLHIN's to create a city-wide profile of health inequities and inform action across the health sector to reduce these inequities.

## COMMENTS

### The Importance of Socio-Demographic Data Collection

Reducing health inequities requires an understanding of the individuals and communities currently served; key communities and populations not being served; the nature and extent of health disparities; and the socio-economic barriers that marginalized populations face in accessing health care and services. The routine collection of client socio-demographic data would achieve this, and enable the health sector to design appropriate interventions to reduce disparities (Institute of Medicine, 2003).

Demographic variables such as race, sexual orientation, and income have not typically been collected in Canadian health care settings.  The little demographic data which does exist is from sources such as Statistics Canada, the Canadian Community Health Survey, or small community and health based organizations. However, these data are difficult to use; each organization asks different questions, in different ways, using different categories for socio-demographic variables such as race.

Linking client-level demographic data to client-level health outcomes enables researchers to analyze the relationship between social identity and health disparities. For example:

- What parts do poverty and racial discrimination play in causing poor health?
- Are racialized LGBT people at greater health risk than their counterparts?
- Can we tease out disability as an indicator of poverty, and therefore poor health?

Socio-demographic data allows us to tackle these health inequities by planning the right interventions to address them.

The dearth of reliable socio-demographic data in Canada is in sharp contrast to the United States where government-mandated data collection on race, ethnicity, preferred language and disability has been in place for decades (Health Research and Education Trust, 2012). As a result, American decision makers have solid information from which to set policies and programs.

## Piloting a Socio-Demographic Data Collection Tool

In 2009, four Toronto health organizations - Mount Sinai Hospital, St. Michael's Hospital, Centre for Addictions and Mental Health (CAMH), and Toronto Public Health – collaborated to develop a standardized socio-demographic data collection tool that was designed to be applicable across the health sector and suited to Toronto's local context. The project, named the Tri-Hospital + TPH Health Equity Data Collection Project, focused on answering the following questions:

- Which socio-demographic variables should be collected?
- Who is best suited to ask clients for sensitive personal information, and at what point in the client encounter?
- Which survey formats maximize response rates? (i.e. paper vs. tablet)
- What solutions would address the lack of interoperability of IT systems across organizations?
- What are best practices for educating clients and staff about the need to collect sensitive personal information?

Over the following two years, a survey tool was developed with 13 socio-demographic variables. The tool was revised with the number of variables narrowed to eight. The final tool was publicly launched in June, 2013 (see Appendix B). The pilot project summary report can be found at (Appendix A):
http://knowledgex.camh.net/health_equity/Documents/Final%20Complendium%20September%202013.pdf

Within TPH, the Healthiest Babies Possible (HBP) program was selected as the pilot site. This is a prenatal nutrition support intervention for pregnant women at risk of having a low weight baby. HPB was selected for the pilot because it serves diverse marginalized populations, and staff already collect personal information when clients enter the program.

## Pilot Results

In 2012, the four project partners used the tool to survey a total of 2,242 clients. The results produced some clear themes:

1) **Clients are willing to share sensitive personal information**
   86.6% of clients answered the survey and 13.4% declined.

2) **The tool could be used in many clinical settings**
   Test sites varied from a family health unit, to schizophrenia services and geriatrics, all with comparably good results, regardless of method.

## Embedding Socio-Demographic Data Collection at TPH

Using the pilot results, TPH is now integrating the eight socio-demographic indicators into sixteen databases.  In addition to the core indicators, TPH likely will also collect age, postal code and housing status. These indicators will be integrated into:

- As many public service areas as possible (approximately 51)
- Research initiatives, when appropriate
- Service planning
- Evaluation and monitoring
- Staff engagement surveys

Beyond assessing client services, socio-demographic data will shine a light on:
- Whether TPH staff reflect the people they serve
- Staff cultural and linguistic assets
- Demographic trends in disease prevalence and health status

In the next two years, TPH will build and implement individual plans for each of 51 client-facing programs. The integration process will be phased in to ensure existing databases, client tracking systems and business processes are aligned for effective and accurate collection of socio-demographic data.

The first database to incorporate the socio-demographic variables will be the Toronto Community Health Information System (TCHIS). TCHIS is an electronic customer management system used to coordinate service requests and delivery to individuals, families and external organizations. It is used by over 750 TPH staff in a wide variety of programs including smoking cessation, food skills, cancer and diabetes prevention, parenting, breastfeeding, and sexual health promotion. TCHIS houses client data for over half of TPH's programs and services.

The integration of core fields into TCHIS is expected by the end of 2014, with data collection beginning in the second quarter of 2015. In addition, socio-demographic data will be collected through TPH's client satisfaction survey, which is being piloted this year.

## Measuring Health Equity at TPH: A Whole Systems Approach

Research in health equity measurement is in its infancy. Other health units and hospitals are also trying to identify the best ways of capturing organizational progress in health equity. TPH is identifying appropriate equity measures for every level of the organization, and created a Health Equity Measurement Framework to guide its work. The Framework consists of four domains (see Appendix C):
- Clients – understanding who we serve and identifying priority populations
- Programs – performance indicators to assess program progress in closing health inequities
- Organization – accountability for whole-of-organization equity goals in areas such as staffing, advocacy and resource allocation
- The City – the health of Torontonians and population level health inequities

## Influencing Change across Health and Other Sectors

A unified Toronto approach to collecting socio-demographic data has the potential to generate a wealth of usable data and information from which to plan and deliver an integrated and coordinated strategy to reduce health inequities. With this in mind, the

Medical Officer of Health met with individuals and organizations to encourage socio-demographic data collection in other sectors, including:

**Ontario Human Rights Commission**
The Medical Officer of Health shared and discussed the findings of the *Racialization and Health Inequities in Toronto* Report as well as the *Tri-Hospital + TPH Health Equity Data Collection* pilot with the Ontario Human Rights Commissioner. TPH and the Commission will continue to explore ways to advance health equity as a human rights issue, and human rights as a health issue.

**Municipal Services**
Tackling health inequities requires action beyond the health sector. City services such as Housing, Employment and Social Services, and Children's Services are critical determinants of health. The Medical Officer of Health met with the City Manager and the Director of Equity, Diversity and Human Rights to brief them on the pilot project and its potential to tackle health and social inequities among City service users. The City Manager is committed to piloting the data collection tool in selected City services. The data will inform program planning to ensure that all residents of Toronto are equitably served.

**Race and Health Research Roundtable**
Toronto Public Health, in partnership with the Centre for Research in Inner City Health (CRICH), convened the city's leading health equity researchers to develop a local race and health research agenda. In March and April 2014, researchers from CAMH, University of Toronto, Toronto District School Board, Access Alliance Multicultural Health Centre, United Way Toronto, and The Wellesley Institute came together to identify local research priorities. The top two research priorities were:
1) Developing a Canadian Measure of Racial Discrimination (working group led by The Wellesley Institute and CRICH).
2) A Socio-Demographic Data Taskforce: to explore opportunities to promote the collection of data across the healthcare sector as well as other sectors such as employment, police, children's services (working group led by TPH and CAMH).

**Other Public Health Units**
Many public health units have contacted TPH about the socio-demographic data collection pilot work (i.e. Peel Public Health, Vancouver Coastal Health). TPH has provided resources and advice to public health units across the country, and through forums such as the National Collaborating Centre on Determinants of Health, and The Ontario Public Health Convention.

## Current Socio-Demographic Information at TPH
Prior to the pilot project, TPH had already been collecting some socio-demographic data. For example, a 2013 Access and Service Satisfaction Survey found that among those who reported using TPH services in the previous 12 months, 60% identified as White, while 35% identified as being members of Indigenous/Aboriginal or racialized communities.

TPH's Employee Engagement Surveys (2010, 2013) also collected socio-demographic data. In 2013, 45.6% of TPH staff identified as White, 32% as members of Indigenous/Aboriginal or racialized communities, 2.5% listed another identity, and 19.9% preferred not to answer or did not know (see Appendix D for additional staff demographic information). And finally, TPH participated in the recent City of Toronto *Count Yourself In*: *Workforce Survey*, which was conducted from June to July 2014. One of the Survey's objectives was to assess the demographic composition of the Toronto Public Service.

Analysis of TPH's budget using an equity lens will be possible only when the eight socio-demographic fields are fully integrated in the 16 databases that collect our client information. It is currently not possible to determine which of TPH's clients are racialized, what portion of our budget supports services to racialized people, and whether TPH resources are equitably distributed.  Toronto Public Health anticipates that by 2016 it will be possible to generate a wealth of equity information, including the distribution of our resources as it relates to health equity.

## CONTACT

Ruby Lam
Manager, Access and Equity
Office of the Medical Officer of Health
Toronto Public Health
Tel: 416-392-0955
Email: rlam@toronto.ca

## SIGNATURE


_____
Dr. David McKeown
Medical Officer of Health


## ATTACHMENTS

Appendix A – The Tri-Hospital & TPH Health Equity Data Collection Research Project Report – September 2013
Appendix B – Final Client Socio-Demographic Data Collection Questions
Appendix C – TPH Health Equity Framework
Appendix D – Toronto Public Health Staff Demographics

## References

1. Health Research and Education Trust. *HRET Disparities Tool-Kit: A Tool-kit for Collecting Race, Ethnicity and Primary Language Information from Patients.* 2012. Retrieved July 23: http://www.hretdisparities.org/WhyCNati-4160.php.

2. Institute of Medicine. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare(full printed version).* Washington, DC: The National Academies Press, 2003.

3. Toronto Public Health. *Racialization and Health Inequities in Toronto*. October, 2013.

4. Wray, R., Agic, B., Bennett-AbuAyyash, C., Kanee, M., Tuck, A., Lam, R., Mohamed, A. and Hyman, I for the Tri-Hospital + TPH Steering Committee. (2013). *We ask because we care: The Tri-Hospital + TPH Health Equity Data Collection Research Project Report: Full Report*. Retrieved July 23, 2014: http://knowledgex.camh.net/health_equity/Documents/Final%20Complendium%20September%202013.pdf

## Appendix B: Final Client Socio-Demographic Data Collection Questions

**1. What language would you feel most comfortable speaking in with your healthcare provider?** *Check <u>ONE</u> only*

☐ Amharic
☐ Arabic
☐ ASL
☐ Bengali
☐ Chinese (Cantonese)
☐ Chinese (Mandarin)
☐ Czech
☐ Dari
☐ English
☐ Farsi
☐ French
☐ Greek
☐ Hindi
☐ Hungarian
☐ Italian
☐ Karen
☐ Korean
☐ Nepali
☐ Polish
☐ Portuguese
☐ Punjabi
☐ Russian
☐ Serbian
☐ Slovak
☐ Somali
☐ Spanish
☐ Tagalog
☐ Tamil
☐ Tigrinya
☐ Turkish
☐ Twi
☐ Ukrainian
☐ Urdu
☐ Vietnamese
☐ Other *(Specify):* _____
☐ Prefer not to answer
☐ Do not know

**2. Were you born in Canada?**

☐ Yes
☐ No
☐ Prefer not to answer
☐ Do not know
If <u>no</u>, what year did you arrive in Canada? _____

**3. Which of the following <u>best</u> describes your racial or ethnic group?**
   *Check <u>ONE</u> only*

☐ Asian- East (e.g., Chinese, Japanese, Korean)
☐ Asian- South (e.g., Indian, Pakistani, Sri Lankan)
☐ Asian- South East (e.g., Malaysian, Filipino, Vietnamese)
☐ Black - African (e.g., Ghanaian, Kenyan, Somali)
☐ Black - Caribbean (e.g., Barbadian, Jamaican)
☐ Black - North American (e.g., Canadian, American)
☐ First Nations
☐ Indian - Caribbean (e.g., Guyanese with origins in India)
☐ Indigenous/Aboriginal not included elsewhere
☐ Inuit
☐ Latin American (e.g., Argentinean, Chilean, Salvadoran)
☐ Métis
☐ Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
☐ White - European (e.g., English, Italian, Portuguese, Russian)
☐ White - North American (e.g., Canadian, American)
☐ Mixed heritage (e.g., Black- African and White-North American)
    *(Specify):* _____
☐ Other(s) *(Specify):* _____
☐ Prefer not to answer
☐ Do not know

**4. Do you have any of the following disabilities?**
   *Check __ALL__ that apply*
   ☐ No disabilities
   ☐ Chronic illness
   ☐ Developmental disability
   ☐ Drug or alcohol dependence
   ☐ Learning disability
   ☐ Mental illness
   ☐ Physical disability
   ☐ Sensory disability (i.e. hearing or vision loss)
   ☐ Other *(Specify):* _____
   ☐ Prefer not to answer
   ☐ Do not know

**5. What is your gender?**
   *Check __ONE__ only*

   ☐ Female
   ☐ Intersex
   ☐ Male
   ☐ Trans- Female to Male
   ☐ Trans- Male to Female

   ☐ Other *(Specify):* _____
   ☐ Prefer not to answer
   ☐ Do not know

**6. What is your sexual orientation?**
   **C**heck __ONE__ only
   ☐ Bisexual
   ☐ Gay
   ☐ Heterosexual ("straight")
   ☐ Lesbian
   ☐ Queer

   ☐ Two-Spirit
   ☐ Other *(Specify):*_____
   ☐ Prefer not to answer
   ☐ Do not know

**7. What was your total family income before taxes last year?**
   *Check __ONE__ only*

   ☐ $0 to $29,999
   ☐ $30,000 to $59,999
   ☐ $60,000 to $89,999
   ☐ $90,000 to $119,999
   ☐ $120,000 to $149,999
   ☐ $150,000 or more
   ☐ Prefer not to answer
   ☐ Do not know

**8. How many people does this income support?** _____
   ☐ Prefer not to answer
   ☐ Do not know

**Additional TPH Questions**

9. **What is your age?** _____
10. **What are the first 3 digits of your postal code?** _____

**Optional Questions**

**1. In what language would you prefer to read healthcare information?** *Check <u>ONE</u> only.*

| | | |
|---|---|---|
| ☐ Amharic | ☐ Hindi | ☐ Somali |
| ☐ Arabic | ☐ Hungarian | ☐ Spanish |
| ☐ Bengali | ☐ Italian | ☐ Tagalog |
| ☐ Braille | ☐ Karen | ☐ Tamil |
| ☐ Chinese (Simplified) | ☐ Korean | ☐ Tigrinya |
| ☐ Chinese (Traditional) | ☐ Nepali | ☐ Turkish |
| ☐ Czech | ☐ Polish | ☐ Twi |
| ☐ Dari | ☐ Portuguese | ☐ Ukrainian |
| ☐ Farsi | ☐ Punjabi | ☐ Urdu |
| ☐ English | ☐ Russian | ☐ Vietnamese |
| ☐ French | ☐ Serbian | ☐ Prefer not to answer |
| ☐ Greek | ☐ Slovak | ☐ Do not know |

☐ Other *(Specify):*_____

**2. What is your religious or spiritual affiliation?** *Check <u>ONE</u> only.*

☐ I do not have a religious or spiritual affiliation

| | |
|---|---|
| ☐ Animism or Shamanism | ☐ Native Spirituality |
| ☐ Atheism | ☐ Pagan |
| ☐ Baha'i Faith | ☐ Protestant |
| ☐ Buddhism | ☐ Rastafarianism |
| ☐ Christian, *not included elsewhere on this list* | ☐ Roman Catholic |
| ☐ Christian Orthodox | ☐ Sikhism |
| ☐ Confucianism | ☐ Spiritual |
| ☐ Hinduism | ☐ Unitarianism |
| ☐ Jainism | ☐ Zoroastrianism |
| ☐ Jehovah's Witnesses | ☐ Other *(Specify):* _____ |
| ☐ Judaism | ☐ Prefer not to answer |
| ☐ Islam | ☐ Do not know |

**3. What type of housing do you live in?** *Check <u>ONE</u> only.*

| | |
|---|---|
| ☐ Boarding Home | ☐ Shelter/Hostel |
| ☐ Correctional Facility | ☐ Supportive Housing |
| ☐ Group Home | ☐ Other *(Specify)*: _____ |
| ☐ Homeless/on street | ☐ Prefer not to answer |
| ☐ Own home | ☐ Do not know |
| ☐ Renting | |

# APPENDIX C: TPH HEALTH EQUITY MEASUREMENT FRAMEWORK

## Clients

Questions:
- Who do we serve?
- What percentage of TPH clients are: Newcomers? Aboriginal? Racialized? Have a disability?
- Who do we serve compared to who we want to serve?
- How do our clients compare to the socio-demographics of the city?

Inputs:
- Socio-demographic data collection
- Client health data

How can this data be used:
- Socio-demographic profile of our clients
- Health status of our clients
- Base for service planning

## Program Performance on Equity

Questions:
- Who benefits and to what extent?
- Do clients experience different quality of programming?
- (differences in access to service, outcomes, client satisfaction)
- Are we researching the intended population?

Inputs:
- Service/program delivery data
- Service/program performance measures
- Client health data, customer satisfaction data

How can this data be used:
- Equity progress by program
- Submission for the Equity Diversity & Human Rights Report
- Base for service planning and program improvement

## Organizational Performance on Equity

Questions:
- What percentage of our budget is used for health equity?
- Are staff reflective of the people we serve?
- Are staff equity competent?

Inputs:
- Program data – aggregated, Budget information
- Staff engagement survey
- Service Plans, Strategic Plan

How can this data be used:
- TPH progress in health equity
- Organizational accountability – e.g., BOH, OPHS

## Toronto's Population Health

Questions:
- How healthy is Toronto's population?
- Are we reducing health inequalities?

Inputs:
- Population health data
- Demographic data, health outcomes data
- Urban Heart
- Toronto specific studies

How can this data be used:
- Health status reports – eg., Unequal City, Global City, Racialization and Health, Aboriginal Health

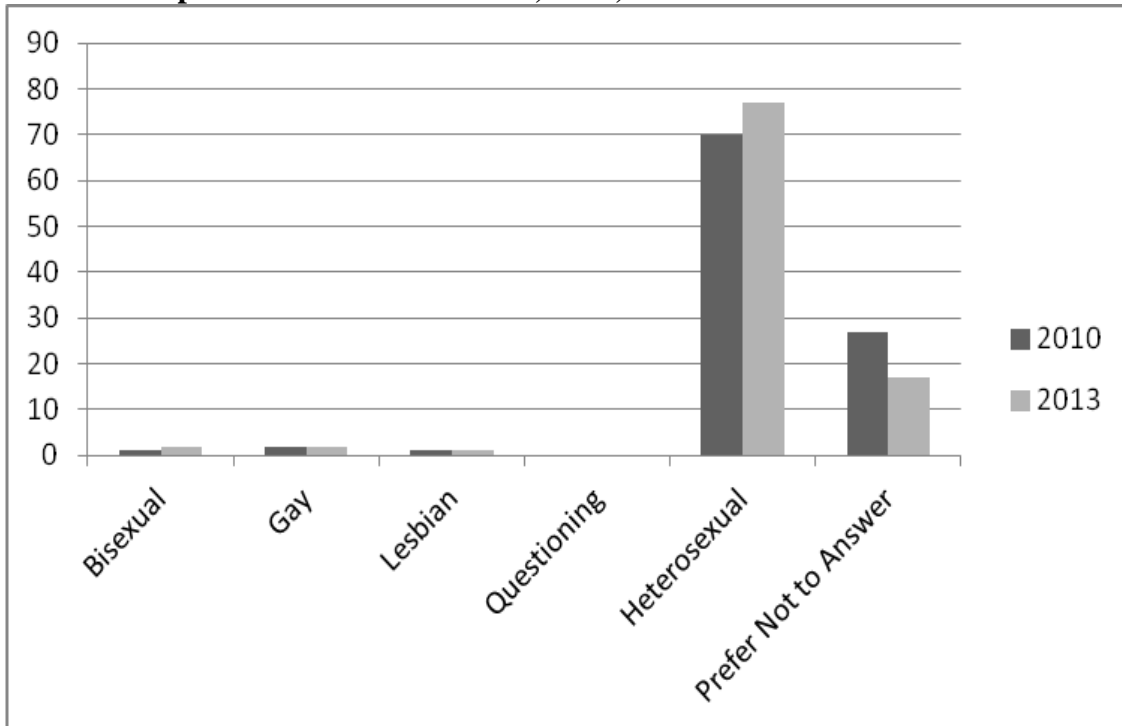## Appendix D: Toronto Public Health Staff Demographics

**Staff Self-Reported Racial/Ethnic Background - 2013**
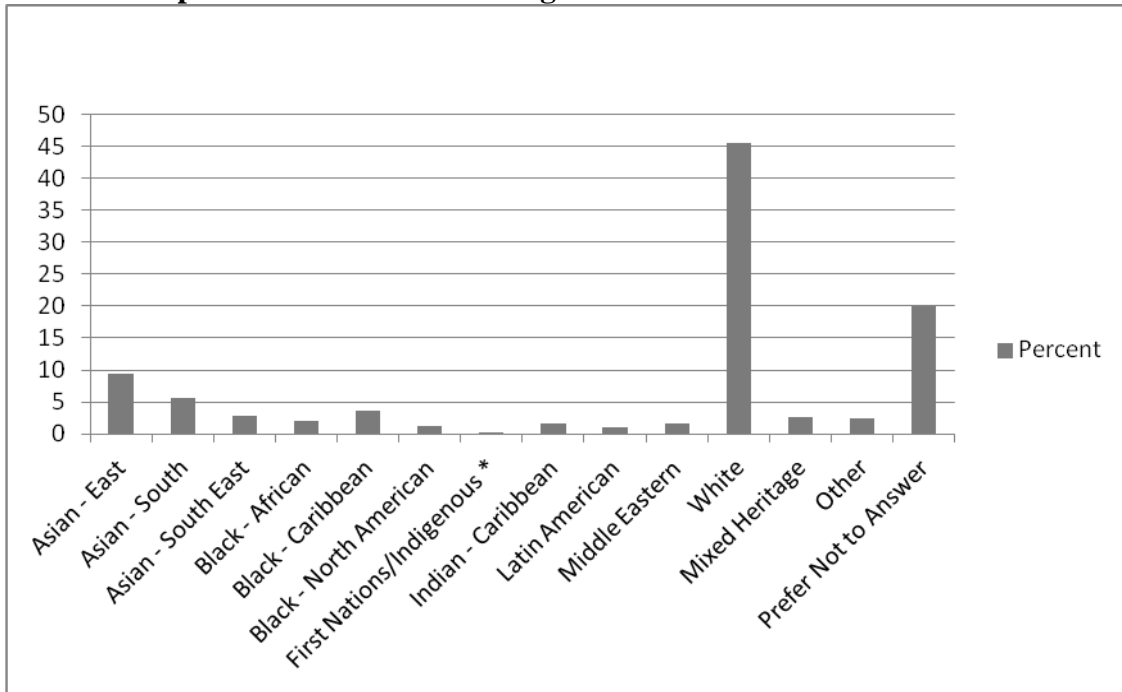


**\*Less than 1%

Note: 2010 data cannot be used to compare to the 2013 results as different racial/ethnic categories were used.

**Staff Self-Reported Sexual Orientation, 2010, 2013**

**Staff Self-Reported Disability, 2010, 2013**