

# Health Equity Questionnaire 2.0: Frequently Asked Questions by Health Care Providers

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## Consent

### What does the consent look like on a mobile phone?

To view how the consent looks on a mobile phone please click the following link which will take you to a test version of the survey:

[https://ocean.cognisantmd.com/questionnaires/preview/QuestionnairePreview.html?ref=do\\_not\\_use\\_upstream\\_&siteNum=1003](https://ocean.cognisantmd.com/questionnaires/preview/QuestionnairePreview.html?ref=do_not_use_upstream_&siteNum=1003)

### Is there a clear, bold line to inform patients they can skip the questions?

Yes, you can review the consent here:

[https://ocean.cognisantmd.com/questionnaires/preview/QuestionnairePreview.html?ref=do\\_not\\_use\\_upstream\\_&siteNum=1003](https://ocean.cognisantmd.com/questionnaires/preview/QuestionnairePreview.html?ref=do_not_use_upstream_&siteNum=1003)

### Is it clear that completing the survey is optional?

The consent form clearly indicates that completing the survey is voluntary and/or that the patient can choose "prefer not to answer" for any/all questions. To view the consent, please click the link below:

[https://ocean.cognisantmd.com/questionnaires/preview/QuestionnairePreview.html?ref=do\\_not\\_use\\_upstream\\_&siteNum=1003](https://ocean.cognisantmd.com/questionnaires/preview/QuestionnairePreview.html?ref=do_not_use_upstream_&siteNum=1003)

To make the consent process more accessible, we are also developing videos to explain "What the HEQ 2.0 Survey is" and "Why we are asking patients to complete the HEQ 2.0" survey, indicating that it is entirely voluntary.

### How are you supporting patients to consent who require language support?

We are exploring opportunities to apply for funding to translate the tool into the top languages spoken by FHT patients. To make the consent process more accessible, we are also developing videos to explain "What the HEQ 2.0 Survey is" and "Why we are asking patients to complete the HEQ 2.0" survey, indicating that it is entirely voluntary.

### Are there easy mechanisms to remove data if a patient requests or withdraws consent?

Yes, if a patient would like their data removed from their chart, they can inform their provider or any staff member who will then message Lisa Miller, and she can clear the responses from the chart.

## Data Governance

### What type of consultation was undertaken in developing the survey?

This project and work is not new and has undergone much consultation over time. A previous version of the Health Equity Questionnaire (HEQ 1.0) was used in our Department beginning in 2013. The development of the original health equity survey emerged from the “We ask because we care” project, which was shaped by research and consultation<sup>1</sup>.

In addition to the development of the current SPARK tool (referred to as the HEQ 2.0 at SMH AFHT) it was developed with consultation from:

- patient partners
- researchers
- clinicians
- policy makers

There was also input from specific organizations including but not limited to:

- the Canadian Institute for Health Information (CIHI)
- StatsCanada
- Ontario Health
- Better Outcomes Registry and Network (BORN)
- Health Data Research Network Canada (HDRN)
- Canada Health Infoway

This survey was also developed following the Engagement, Governance, Access, and Protection (EGAP) framework<sup>2</sup>, a tool that guides the collection, management, analysis and use of race-based data from Black communities in ways that advance health equity and dismantle anti-Black racism.

### How are we ensuring that all patient data is treated with consideration and thoughtfulness?

We at the SMH AFHT are committed to not analyzing the HEQ 2.0 data before having a "Data Use Retreat" where we will be engaging providers, patient advisors, lived experience experts and other collaborators to provide insights on how to prioritize analysis and application of the data in a way that promotes benefit to our patients and communities and avoids harm. We intend to have this data retreat in late 2024. Before this time we will only be analyzing HEQ 2.0 response rates.

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<sup>1</sup> We ask because we care: The Tri-Hospital + TPH Health Equity Data Collection Research Project Report. September 2013. < <http://torontohealthequity.ca/wp-content/uploads/2017/05/We-Ask-Because-We-Care-Report.pdf>>

<sup>2</sup> Black Health Equity Working Group. (2021). *Engagement, governance, access, and protection (EGAP): A data governance framework for health data collected from Black communities*.

## Data Quality

### Why are you asking about ethnicity in addition to race?

Including ethnicity is a patient-focused question that promotes inclusion. Research done regarding collecting data on race and ethnicity highlighted that "non-white participants reiterated the importance of ethnic uniqueness. They called for including ethnic uniqueness in standard patient surveys administered in healthcare settings to capture race and ethnic data. For instance, participants who identified as African believed their ethnic identity was unique and different from black Canadians born and raised in Canada."<sup>3</sup> Similarly, research has shown that asking about ethnicity is complex, particularly in diverse populations of mixed heritage. Allowing patients to self-identify using free text responses (as the HEQ 2.0 does) is helpful<sup>4</sup>.

## Implications of Data

### What are the implications of having sensitive info on the patient's chart? Specifically, what are the implications for insurance purposes?

The data collected from the HEQ 2.0 **does not** get uploaded to the CPP. As a part of the new Release of Information protocol (outlined during the October medical staff meeting) data from the HEQ 2.0 will not be included when medical charts are requested by third parties.

### Is there any evidence that the data generated from HEQ 1.0 improved care at the individual or population level?

The data generated from HEQ 1.0 supported several research studies and quality improvement projects to support patients.

For example, research from our Department showed that patients living below the low income cut-off (LICO) were less likely to undergo cancer screening<sup>5</sup>. Subsequent research on patients living with low income designed solutions on how to increase cancer screening rates<sup>6</sup>. Additional research showed that trans patients were less likely than cis patients to be screened for cancer<sup>7</sup>.

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<sup>3</sup> Seshie, Zita et al. Perspectives of Canadians on Being asked about Race and Ethnicity in Healthcare Settings. [Submitted for Publication]

<sup>4</sup> Kiran T, Sandhu P, Aratangy T, Devotta K, Lofters A, Pinto AD. Patient perspectives on routinely being asked about their race and ethnicity: Qualitative study in primary care. *Can Fam Physician*. 2019 Aug;65(8):e363-e36

<sup>5</sup> Lofters AK, Schuler A, Slater M, Baxter NN, Persaud N, Pinto AD, Kucharski E, Davie S, Nisenbaum R, Kiran T. Using self-reported data on the social determinants of health in primary care to identify cancer screening disparities: opportunities and challenges. *BMC Fam Pract*. 2017 Feb 28;18(1):31.

<sup>6</sup> Lofters AK, Baker NA, Schuler A, Rau A, Baxter A, Baxter NN, Kucharski E, Leung FH, Weyman K, Kiran T. A "Tea and Cookies" Approach: Co-designing Cancer Screening Interventions with Patients Living with Low Income. *J Gen Intern Med*. 2020 Jan;35(1):255-260.

<sup>7</sup> Kiran T, Davie S, Singh D, Hranilovic S, Pinto AD, Abramovich A, Lofters A. Cancer screening rates among transgender adults: Cross-sectional analysis of primary care data. *Can Fam Physician*. 2019 Jan;65(1):e30-e37.

Subsequent to this research, Drs Aisha Lofters and Tara Kiran developed a toolkit, based on this research and patient engagement, on how to Improve Cancer Screening Rates to Reduce Disparities<sup>8</sup>.

We recognize that data collection is just one step to inform and guide action that benefits patients by supporting health equity.

### What are the implications of unconscious bias and gaps in knowledge/skills in physicians/providers seeing this data in the patient's chart?

We aim to ensure that the benefits of providers knowing the social and personal characteristics of their patient outweighs the potential harms.

In the context of SMH AFHT, much work has been done by the SDOH Committee, anti-racism advisory committee and others to mitigate harm. Over the past few years our Department has promoted and invested in anti-racism education and training for Department members and leaders to help us recognize and neutralize our unconscious bias.

It is felt that the benefits to providers knowing the social issues outweigh the potential harms. For example, suppose a patient identifies needs on the survey. In that case, providers can see this information and address it (by providing resources, referrals etc). If providers were not able see their patient's HEQ data, patients may not receive that direct individual benefit of data collection.

## Implementation Considerations

### What is your implementation approach?

Our implementation approach is an iterative one. Although we are beginning with recruitment via email alone, this is not our entire plan. We know we will miss a large portion of our patients and populations with this approach alone.

Our Department's Health Equity Survey QI project team spent several months trying to organize a process of including volunteers in our waiting rooms to assist patients with completing the survey. After several months of discussions with Unity Health's legal department it became clear that we, unfortunately, cannot recruit volunteers to support this work.

The project team then submitted a grant application to study how best to collect health equity data from hard-to-reach populations, including those individuals with no email address, no fixed address, patients living in lower-income communities, etc. We were successful in obtaining this grant which will allow the Department to hire a Community Surveyor to reach out to 50% of our "hard to reach populations" to support them in completing the survey. We can also hire Virtual Surveyors so providers can book patients who need support to receive a phone call from an individual to complete the survey over the phone. For the study, the Community Surveyor will only be available for patients at 80 Bond

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<sup>8</sup> Lofters, A. Kiran, T. Improving cancer screening rates in your practice and reducing related disparities<  
<https://maphealth.ca/wp-content/uploads/2019/11/MAP-toolkit-for-health-care-professionals-Improving-cancer-screening-rates-in-your-practice-and-reducing-related-disparities.pdf>>

and St. Lawrence (the study sites included in the grant). The Virtual Surveyors will be available to all sites.

We hope this study will serve as a business case to help us secure funding to maintain and scale up these critical roles.

### How are you taking into account bias in that those who are more socially advantaged are more likely to complete the survey?

Research done on the implementation of HEQ 1.0 highlights that there are differences in who responds.<sup>9</sup> In our implementation process we will be monitoring and tracking who responds to the HEQ 2.0 (to estimate non-response bias). Future research may also explore how to weigh data responses so that it is more representative of the whole FHT patient population.

This is also why additional strategies are being put in place to target recruitment of typically non-represented patients. *Please see response to “What is your implementation approach?” for additional details.*

### How are you ensuring that marginalized patients will be represented in data collection?

*Please see response to “What is your implementation approach?”*

### What % of patients have reliable email addresses, internet and capacity to answer e-survey?

As of June 2023, 75% of patients of the FHT have an email address on file. How we plan to reach the other 25% is summarized in the response to “What is your implementation approach?”

### How are clerical and clinical staff being trained to help those who can't complete it?

Currently, clerical staff are not expected to help patients complete the survey. They are being provided training, so if patients ask about it, they understand the initiative and know how to respond. Clinical staff will also be trained so that they can help explain the HEQ questionnaire to patients.

As mentioned above there will be Virtual Surveyors hired who can assist patients in completing the survey over the phone. *Please see response to “What is your implementation approach?” for additional details.*

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<sup>9</sup> Pinto, A. et al. Evaluating robust sociodemographic data collection within a primary care setting: Final Report and Recommendations. < <https://maphealth.ca/wp-content/uploads/Health-Equity-Data-study-final-report-Oct-10-2017.pdf>>