

# Patient perspectives on routinely being asked about their race and ethnicity

## Qualitative study in primary care

Tara Kiran MD MSc CCFP FCFP Priya Sandhu Tatiana Aratangy PhD  
Kimberly Devotta MA Aisha Lofters MD PhD CCFP Andrew D. Pinto MD CCFP FRCPC MSc

### Abstract

**Objective** To understand patients' perspectives on responding to a question about their race and ethnicity in a primary care setting.

**Design** Qualitative study using semistructured individual interviews conducted between May and July 2016.

**Setting** An academic family health team in Toronto, Ont, where collection of sociodemographic data has been routine since 2013.

**Participants** Twenty-seven patients from 5 of the 6 clinic sites of the family health team, ranging in age, sex, educational background, and immigration status.

**Methods** Semistructured interviews were conducted with patients who completed a sociodemographic questionnaire after registration for their medical appointment. Patients were asked whether responding to the question was difficult or uncomfortable, how they interpreted the term *race and ethnicity*, and what response options they considered. Interviews were audiorecorded, transcribed, and coded iteratively.

**Main findings** Patients did not report discomfort with responding to a question about race and ethnicity in their family doctor's office. Although many patients considered the question straightforward, some patients reported different interpretations of the question. For example, some thought the question about race and ethnicity related to parental origin or ancestry, whereas others considered the question to be about personal place of birth or upbringing. Many patients appreciated being able to select from a variety of specific response options, but this also posed a difficulty for patients who could not easily find an option that reflected their identity. Patients with mixed heritage experienced the most challenges selecting a response.

**Conclusion** Patients attending a primary care clinic were not uncomfortable responding to a question about race and ethnicity. However, patients had different interpretations of what was being asked. Future research should explore perspectives of patients in other primary care settings and test different methods for collecting data about their race and ethnicity.

### Editor's key points

▶ Collecting data on race and ethnicity is an important step in understanding and addressing known racial and ethnic disparities in health care and health outcomes. This study aimed to explore patients' comfort and thought processes when responding to the question about their race and ethnicity.

▶ This study found that patients were not uncomfortable disclosing their race and ethnicity on a sociodemographic data questionnaire. Many patients intuitively understood how the data could be helpful for their health care providers. Patients interpreted the meaning of the term *race and ethnicity* in different ways. Most patients assumed that it pertained to their heritage, culture, or parents' background. However, some interpreted it to mean one's own place of birth and upbringing. Others expressed confusion about how race and ethnicity were different, and this confusion made it difficult for them to answer the question. Challenges with interpreting and answering the question about race and ethnicity were pronounced for patients of mixed heritage.

▶ Future research should gather recommendations from patients attending primary care organizations in a variety of communities across Canada on how to explain the purpose of race and ethnicity data collection, optimal wording for how to ask the question, and related response options.



## Points de repère du rédacteur

► La collecte de renseignements sur la race et l'ethnicité est une étape importante pour comprendre et aborder les disparités raciales et ethniques connues dans les soins de santé ainsi que les résultats en matière de santé. Cette étude avait pour but de chercher à connaître le niveau de confort et les processus de réflexion des patients lorsqu'ils répondent aux questions concernant leur race et leur ethnicité.

► Cette étude a révélé que les patients ne sont pas mal à l'aise de divulguer leur race et leur ethnicité dans un questionnaire sur les données sociodémographiques. Beaucoup de patients comprenaient par intuition comment ces données pourraient être utiles à leurs professionnels de la santé. Les patients ont interprété différemment le sens des mots *race* et *ethnicité*. La plupart des patients ont présumé que ces mots signifiaient leur origine, leur culture ou les antécédents de leurs parents. Par ailleurs, certains ont interprété leur sens comme étant leur lieu de naissance et l'endroit où ils ont grandi. D'autres ont exprimé leur confusion quant à la différence entre race et ethnicité, et cette confusion leur a rendu plus difficile de répondre à la question. Les difficultés d'interprétation et de réponse à la question sur la race et l'ethnicité étaient plus prononcées chez les patients d'origines mixtes.

► D'autres études de recherche devraient recueillir des recommandations auprès de patients qui fréquentent des milieux de soins primaires dans une diversité de régions du Canada quant aux meilleures façons d'expliquer le but de la collecte de données sur la race et l'ethnicité, la formulation optimale de la question et les choix de réponses connexes.

# Points de vue des patients sur le questionnement systématique à propos de leur race et de leur ethnicité

## Étude qualitative en soins primaires

Tara Kiran MD MSc CCFP FCFP Priya Sandhu Tatiana Aratangy PhD  
Kimberly Devotta MA Aisha Lofters MD PhD CCFP Andrew D. Pinto MD CCFP FRCPC MSc

### Résumé

**Objectif** Comprendre les points de vue des patients lorsqu'ils sont questionnés sur leur race et leur ethnicité dans les milieux de soins primaires.

**Type d'étude** Étude qualitative à l'aide d'entrevues individuelles semi-structurées effectuées entre mai et juillet 2016.

**Contexte** Une équipe universitaire de santé familiale à Toronto (Ontario), qui recueille des données sociodémographiques de façon systématique depuis 2013.

**Participants** Vingt-sept patients fréquentant 5 des 6 cliniques de l'équipe de santé familiale, dont l'âge, le genre, le niveau d'instruction et le statut d'immigration varient.

**Méthodes** Des entrevues semi-structurées ont été effectuées avec des patients qui avaient répondu à un questionnaire sociodémographique après s'être inscrits à leur rendez-vous médical. On a demandé aux patients s'il était difficile ou inconfortable de répondre à la question, quelle était leur interprétation des mots race et ethnicité, et quels choix de réponse ils avaient considérés. Les entrevues ont fait l'objet d'un enregistrement audio et d'une transcription, puis ont été codées itérativement.

**Principales constatations** Les patients n'ont pas signalé de malaise à répondre à une question au sujet de la race et de l'ethnicité à la clinique de leur médecin de famille. Même si de nombreux patients trouvaient la question simple, certains ont rapporté différentes interprétations à cette question. Par exemple, certains croyaient que la question au sujet de la race et de l'ethnicité concernait l'origine parentale ou ancestrale, d'autres pensaient que la question avait trait au lieu de leur naissance ou à celui où ils avaient grandi. De nombreux patients ont aimé pouvoir choisir parmi divers choix de réponse spécifiques, mais ces choix ont aussi posé des difficultés aux patients qui ne pouvaient pas trouver facilement un choix qui reflétait leur identité. Les patients ayant des origines mixtes ont éprouvé plus de difficulté à choisir une réponse.

**Conclusion** Les patients qui fréquentaient une clinique de soins primaires n'étaient pas mal à l'aise de répondre à une question à propos de la race et de l'ethnicité. Par ailleurs, les patients interprétaient différemment ce qui leur était demandé. D'autres études de recherche devraient explorer les points de vue des patients dans d'autres milieux de soins primaires et mettre à l'essai différentes méthodes visant à recueillir les données à propos de leur race et de leur ethnicité.

## — Methods —

Canadians pride ourselves on our universal health insurance system that aims to provide medically necessary services to everyone regardless of background. Despite universality of coverage, racial inequalities in health persist even after accounting for socioeconomic factors.<sup>1</sup> The magnitude and types of inequalities are different from those observed in the United States, underlining the importance of research specific to the Canadian context.<sup>1,2</sup> Race is a socially constructed, arbitrary classification of people based on skin colour and other physical characteristics.<sup>3</sup> Ethnicity is based on self-identification and refers to shared traits based on ancestry, social background, culture, tradition, and language.<sup>3</sup> Issues of race and ethnicity are particularly relevant in Canada given our multiracial and multiethnic population. For example, Canadians report more than 200 different ethnic origins, with 13 different ethnic origin groups having a population of more than 1 million each.<sup>4</sup>

Organizations that address health care and human rights have advocated for the collection of race and ethnicity data in health care as a way to monitor and reduce inequities in quality of care.<sup>5,6</sup> Health care organizations in Canada have recently begun a dialogue to explore the collection of race and ethnicity data.<sup>7,8</sup> There is an interest in moving beyond broad categories such as “visible minorities,” which can obscure differences between specific racial or ethnic groups.<sup>9</sup> Primary care is increasingly seen as an ideal venue to collect detailed sociodemographic data and take action to improve care and reduce health inequities where identified.<sup>10</sup> Primary care practitioners recognize the effects of social determinants on health and also have the ability to act on these at the point of care and at the level of the practice population.<sup>11-13</sup>

Despite these directions, it is unclear how patients would react to the collection of race and ethnicity data. Self-identification of race and ethnicity is complex, as it relates to how we see ourselves, the histories of our families and our communities, how others see us and affix labels to us that we do and do not agree with, and how we relate to others.<sup>14-16</sup> A handful of studies have explored the views of Canadians on the collection of race and ethnicity data in health care settings, but these studies occurred outside the primary care context and results have been mixed.<sup>17-19</sup> No Canadian studies have explored the reactions of primary care patients to the collection of race and ethnicity data in a primary care setting. Since 2013, our primary care practice has been routinely asking patients to complete a questionnaire about sociodemographic characteristics that includes a question on race and ethnicity.<sup>20</sup> Our study aimed to understand the perspectives of patients who completed the sociodemographic data questionnaire and explore their comfort and thought processes when responding to the question about race and ethnicity.

The study was conducted at the St Michael’s Hospital Academic Family Health Team in Toronto, Ont, an inter-professional primary care organization serving more than 43 000 patients at 6 clinic sites in downtown Toronto. Since 2013, clerical staff for this family health team routinely ask patients who register for an appointment to complete the sociodemographic data questionnaire, provided the patient has not responded within the past 3 years. Patients complete the questionnaire on a tablet computer or on paper, and their responses are linked to their medical chart. There are 11 questions in total, including 1 question asking respondents to describe their racial or ethnic group (**Box 1**). (To retrieve a copy of the full questionnaire, contact the corresponding author [T.K.]. More information about the questionnaire can also be found at <http://torontohealthequity.ca>.) Some response options relate strictly to geography, while others incorporate both race and geography. Many response options include examples of relevant countries. Questions were developed by a collaborative regional process and pilot-tested for feasibility and acceptability.<sup>20,21</sup>

We conducted a qualitative study to understand patient perspectives on answering the questions about their sociodemographic characteristics. The study was reviewed and approved by the Research Ethics Board at St Michael’s Hospital. In this article, we report on the findings related to the question on race and ethnicity.

### **Box 1. Question on race and ethnicity that was presented to patients as part of the self-administrated sociodemographic questionnaire distributed to patients at clinic registration**

Which of the following best describes your racial or ethnic group? Choose 1.

- Asian – East (eg, Chinese, Japanese, Korean)
- Asian – South (eg, Indian, Pakistani, Sri Lankan)
- Asian – Southeast (eg, Malaysian, Filipino, Vietnamese)
- Black – African (eg, Ghanaian, Kenyan, Somali)
- Black – Caribbean (eg, Barbadian, Jamaican)
- Black – North American (eg, Canadian, American)
- First Nations
- Indian – Caribbean (eg, Guyanese with origins in India)
- Indigenous or Aboriginal not included elsewhere
- Inuit
- Latin American (eg, Argentinian, Chilean, Salvadoran)
- Metis
- Middle Eastern (eg, Egyptian, Iranian, Lebanese)
- White – European (eg, English, Italian, Portuguese, Russian)
- White – North American (eg, American, Canadian)
- Mixed heritage (eg, black African and white North American)
- Other
- Prefer not to answer
- Do not know

Between May and July 2016, research staff recruited patients from 5 of the 6 clinics. The sixth clinic was not routinely collecting patient sociodemographic characteristics when the study began. Patients who completed the sociodemographic data questionnaire were approached immediately afterward in the waiting room by a research staff member to participate in the study. Research staff did not have access to any of the completed responses. Participants needed to be 18 years of age or older and comfortable conversing in English. Two research staff members conducted the interviews—1 staff member was white and the other staff member was not white. Interviews were done in a private room either before or after a patient's medical appointment, whichever was most convenient for the patient.

Research staff conducted semistructured individual interviews with patients using cognitive interviewing techniques. Interviews began with a short survey asking patients which questions they found difficult or uncomfortable to answer. The semistructured interview probed patients' reasons for why they reported finding the question difficult or uncomfortable. Interviews also probed patients' understanding of the term *racial or ethnic group* and what response options the patients had considered. Following the interview, research staff collected some basic information on demographic characteristics. Staff monitored these data and, to the degree possible, they modified recruitment to ensure participants came from varied backgrounds. The interviews, including probes on multiple sociodemographic questions, averaged 29 minutes in length. Research staff also recorded observations in the waiting room during clinic visits.

Interviews were audiorecorded and transcribed. Data were coded by 5 study team members using an iterative process, until we achieved saturation in key themes. The initial codebook was developed by having each team member independently review and code the same few interviews. Codes were then reviewed and refined by the group using a consensus process. Coding was done in 2 subsequent rounds with revision of codes in between rounds. Interrater reliability was calculated as more than 90% in both rounds of coding. Coded data were reviewed by the larger study team to identify overarching themes including areas of consensus, as well as contradictory observations. All analyses were done using NVivo 9.

## — Findings —

Twenty-seven patients from 5 clinics were interviewed. Participants ranged in age, sex, educational background, immigration history, and health status, but most reported that English was their preferred language (Table 1).

### Participant responses

Interviews with patients about their perspectives on answering a question about race and ethnicity revealed the following.

**Different interpretations of what the question was asking.** Many patients reported that the question was easy to understand. At the same time, they interpreted the question in different ways. Most patients believed that the question was asking about one's family background in terms of his or her ancestry: "So that's just background, like where my parents are from, where my grandparents are from .... Kind of culture that they I guess follow .... Ancestry."

But, others thought that *ethnicity* referred to one's own place of birth and place of upbringing.

Just North American was more generic. I could have said European, but I guess in one sense I was born in Canada and so, I'm just Canadian ... I'm not a person [or] someone that gets held up on heritage too much. It's about I think about, now, and where we are now.

**Table 1. Demographic characteristics of the 27 participants**

CHARACTERISTICS	NO. OF PARTICIPANTS
Age, y	
• 18-24	<6
• 25-34	<6
• 35-49	8
• 50-64	7
• ≥ 65	<6
Sex	
• Female	18
• Male	<6
• Other	<6
Highest education level	
• Less than high school	<6
• Completed high school	6
• Completed college	<6
• Completed university	13
Preferred language	
• English	20
• Not English	7
Born in Canada	
• Yes	15
• No	12
Self-rated health	
• Excellent or very good	9
• Good	9
• Fair or poor	9

\*Cell sizes <6 have been suppressed to reduce the risk of participant re-identification.



**Ease of selecting a response.** Most patients appreciated the variety of response options.

Again, super great on the amount of choice that you have. Like, it's really cool. It's not just, like, 1 option for Asian; it's, like, taking into consideration the different parts of Asia and how, like, different they are and kind of all that. It's really, like, inclusive.

I like that it wasn't just Caucasian ... I enjoyed that there was a bit more breadth to that. Again I like that fact that there was a bit more detailed ... *Caucasian* is so broad .... And using terms like that are so broad I thought the specificity of it was very good.

Patients who described the most difficulty answering this survey question were children of immigrants or those of mixed heritage. Patients were unsure if they should include the place they were born, where they were raised, or their parental or ancestral origins.

I mean, my parents are from India but we lived most of our lives in Hong Kong before I moved to Canada .... and it's also confusing if it's asking about racial group or ethnic group.

Well, you know it said, "white European" blah blah blah, and my father was English and my mother was Ukrainian. I am white, you know, Caucasian, but you know they were European. Then I saw the next English category that said "Canadian North American," which is what I am, you know—I've come from that—but you know I am born and bred in Canada. So that was just a little bit confusing. It's like, "What kinda white person am I?" [Laughs]

Some patients had difficulty selecting an answer from among the available response options.

I'm mixed race but I'm Caribbean mixed race .... See, I'm not really a black Caribbean—Barbadian or Jamaican. I'm not black North American. I'm not really Asian. I'm obviously not First Nations, Indigenous, not even Latin American, not really, you know? Because I'm not from that part of Latin America. I'm from South America but not the Latin American part. I'm certainly not Middle Eastern. Not white. I'm mixed heritage, I guess. But see, you have "black African" and "white North American," so there are other mixed heritages that are not included in this group that are common .... I just put "other."

Available response options also influenced how patients of mixed heritage self-identified.

So my dad's Indian and my mom's Caucasian, so I found that whatever term you guys are using for ...

I think it's *biracial*, I can't remember, but I think originally I was going to answer, like, just white, like North American, so that was there, so I found it ... the way I was reading, so the way me, my brothers and sisters turned out, we're all white, right; my dad probably finds it a little strange. So that's typically how we identify if we're not offered a ... like and I talked to my sibs about this, right; if we're not offered a mixed-heritage answer in a simple questionnaire like that, so it's just what I default to. But then when I saw the ... that "mixed heritage" answer, that's what I chose.

**Perceptions about the question and its purpose.** Most patients did not report feeling uncomfortable about being asked the question about race and ethnicity. "To me it doesn't bother me, quite; if I'm asked what is my background, it's Latin American. I'm very proud of it."

Many patients believed it was relevant or important for patients to be asked about their race and ethnicity.

Yeah, I thought for this kind of survey it's a necessary thing.

Yeah, I mean basically is asking "what your skin colour is and where you are from" ... I think in terms of, like, health equity, like, it's helpful to know that because, like, sometimes we face a lot of discrimination.

Although patients did not mention personal fears about discrimination, some believed that the question could make others feel uncomfortable.

## — Discussion —

We found that patients attending an urban Canadian primary care practice were not uncomfortable disclosing their race and ethnicity on a sociodemographic data questionnaire linked with their medical chart. Many patients intuitively understood how the data could be helpful for their health care providers. Patients interpreted the meaning of *race and ethnicity* in different ways. Most patients assumed that the term pertained to their heritage, culture, or parents' background. However, some interpreted it to mean one's own place of birth and upbringing. Others expressed confusion about how race and ethnicity were different, and this confusion made it difficult for them to answer the question. Challenges with interpreting and answering the question were pronounced for patients of mixed heritage.

Studies from the United States have found that patients support the idea of hospitals and clinics collecting data on patient race and ethnicity, especially to monitor disparities in care.<sup>22,23</sup> However, almost half of the non-white respondents in these studies worried that these data could be used to discriminate against them or others, and many respondents said they would feel uncomfortable providing the information. Telephone

surveys conducted nationally<sup>19</sup> and in 2 different regions in Canada<sup>17,24</sup> found between 15% and 30% of people would be uncomfortable with a health care organization collecting data on ethnic background. A large qualitative study in western Canada raised concerns from patients and ethnocultural community leaders about considerable potential harm from both having ethnicity data and the process of data collection.<sup>18</sup> All of these studies asked patients about the theoretical acceptability of data collection, whereas our study probed the reactions of patients who had already provided their own data. Few patients in our study reported any discomfort with the question and none expressed worry that the data could be used to discriminate against them. The high comfort levels we found might relate to our study taking place within a primary care setting where patients had an ongoing, trusting relationship. Other studies have indicated that patients felt most comfortable with the idea of ethnicity data being collected by a family physician.<sup>24</sup> Clerical staff at our practice did not provide a detailed explanation of the purpose of the data collection, a strategy found to increase patient comfort.<sup>25,26</sup> We did not interview any patients who refused to complete the sociodemographic data questionnaire, but our previous work found that few (7%) refuse.<sup>13</sup>


Our findings shed light on the complexity of asking information about patients' race and ethnicity in an ethnically diverse population that includes many people of mixed heritage. Many patients self-identified with more than 1 racial or ethnic group. Although patients in our study appreciated the multitude of potential response options, experts have suggested that allowing patients to self-identify using free-text responses can be particularly useful.<sup>25</sup> Free-text responses can more accurately reveal perceived self-identity and community affiliation; might enable targeted interventions for specific minority populations; are preferred by patients of mixed heritage; and can potentially be aggregated using computer-generated algorithms.<sup>27</sup> Alternatively, organizations can allow respondents of mixed heritage to select more than 1 response that applied to them. Organizations can also provide more specific instruction, for example, whether respondents should preferentially indicate ancestral country of origin, own place of birth, racial background, or current cultural identity. Clarifying the purpose for data collection might help organizations decide on the approach for data collection and how to guide respondents. Although granular race and ethnicity data have many theoretical benefits and can be used at the point of care,<sup>25</sup> small samples in any 1 category can make it challenging to use the data for health care improvement and research.<sup>28</sup>

### Strengths and limitations

Our study has both strengths and limitations. We are the first Canadian study to understand the perspectives of patients who have completed a sociodemographic data

questionnaire that includes a question on race and ethnicity. However, our study occurred in a single primary care organization—one of only a few in Canada that have been collecting sociodemographic data routinely for a few years. Our practice is located in Toronto, a large urban centre where residents report more than 200 distinct ethnic origins and where approximately half of residents are foreign born.<sup>29</sup> Our city is more diverse than other municipalities in Canada, which provides a unique vantage to understand the perspectives of the growing group of patients of mixed heritage, but this advantage might further limit the generalizability of our findings. Although we probed patients about whether they thought the question on race and ethnicity was difficult or uncomfortable to answer, we did not specifically ask patients their views on potential harms that have been raised by patients elsewhere.<sup>18</sup> Finally, in Canada, Indigenous people experience some of the largest inequalities in health and health care,<sup>1,2</sup> but our study did not specifically explore their views. Unfortunately, the sociodemographic data questionnaire was not developed using principles of ownership, control, access, and possession, the standard for conducting research with Indigenous people.<sup>30</sup> The regional health authority is currently in dialogue with Indigenous leaders to ensure the questionnaire meets the needs of and standards for Indigenous people.

### Conclusion

We found that patients in an urban primary care practice who had completed a self-administered sociodemographic data questionnaire did not express discomfort with answering a question about race and ethnicity. Patients interpreted the question in different ways. Most patients interpreted the question as asking about ancestral origins while some thought it was asking about one's own country of birth and upbringing. Patients of mixed heritage experienced unique challenges to responding to the question. Future research should gather recommendations from patients attending primary care organizations in a variety of communities across Canada on how to explain the purpose of race and ethnicity data collection, optimal wording for how to ask the question, and related response options. When considering the collection of race and ethnicity data in health care, response categories should more intuitively reflect the lived experience of patients' lives. 

**Dr Kiran** is a family physician at St Michael's Hospital Academic Family Health Team in Toronto, Ont, Associate Scientist in the MAP Centre for Urban Health Solutions at the Li Ka Shing Knowledge Institute at St Michael's Hospital, Associate Professor and Vice Chair Quality and Innovation in the Department of Family and Community Medicine at the University of Toronto, and Adjunct Scientist at ICES in Toronto. **Ms Sandhu** is an MD candidate in the Faculty of Medicine at the University of Toronto. **Dr Aratangy** is Unit Lead in the Survey Research Unit at the Li Ka Shing Knowledge Institute at St Michael's Hospital. **Ms Devotta** is a research coordinator at St Michael's Hospital. **Dr Lofters** is a scientist at the MAP Centre for Urban Health Solutions in the Li Ka Shing Knowledge Institute at St Michael's Hospital, a staff physician in the Department of Family and Community Medicine at St Michael's Hospital, Assistant Professor and Clinician Scientist in the Department of Family and Community Medicine at the University of Toronto, Adjunct Scientist at ICES, and Assistant Professor in the Dalla Lana School of Public Health at the University of Toronto. **Dr Pinto** is the founder and director of

the Upstream Lab at the MAP Centre for Urban Health Solutions in the Li Ka Shing Knowledge Institute at St Michael's Hospital, a family physician and public health and preventive medicine specialist in the Department of Family and Community Medicine at St Michael's Hospital, Associate Director for Clinical Research at the University of Toronto Practice-Based Research Network, Assistant Professor in the Department of Family and Community Medicine at the University of Toronto, and Assistant Professor (status only) in the Institute for Health Policy, Management and Evaluation and the Division of Clinical Public Health in the Dalla Lana School of Public Health.

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#### Contributors

**Drs Kiran and Pinto** conceived the study. **Dr Kiran, Dr Aratangy, Ms Devotta, and Dr Pinto** designed the study. **Dr Aratangy and Ms Devotta** were involved in the data collection. All authors were involved in the analysis and interpretation of the data. **Dr Kiran and Ms Sandhu** drafted the manuscript and all authors provided feedback on the draft. All authors approved the final submitted manuscript.

#### Competing interests

At the time of writing, **Dr Kiran** was the Quality Improvement Program Director and Board Chair for St Michael's Hospital Academic Family Health Team. She was also a primary care advisor for the Toronto Central Local Health Integration Network between April 2015 and October 2016. The authors have no other competing interests to declare.

#### Correspondence

**Dr Tara Kiran**; e-mail [tara.kiran@utoronto.ca](mailto:tara.kiran@utoronto.ca)

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