

Expanding Demographic Data Collection into Home and Community Care Toronto Central LHIN

Circle of Care Pilot Report

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Background:

The collection of patient and client demographic data is now considered a gold standard in health equity practices. Ensuring health care organizations and health care providers have access to this data is a necessary first step for understanding who is (not) being served, identifying and addressing inequities, and characterizing patient and client needs.

Since 2013, the Toronto Central Local Health Integration Network (LHIN) mandated the routine collection of patient-level demographic data using a standard set of 8 questions in 16 hospitals and 16 community health centres (see Appendix A). As a result, Sinai Health System has been spearheading this work for 5 years and is seen as a leader in planning and implementing patient/client demographic data collection in diverse health care settings. Accreditation Canada awarded Sinai Health an ‘innovative leading practice’ designation for the efforts in embedding demographic data collection in health care settings.

Expanding data collection:

Equity and the collection of demographic data continue to be a high priority for Toronto Central LHIN, with a long-term aim of capturing demographic data on 75% of the patients and clients they serve. Following the implementation of demographic data collection in hospitals and CHCs, the Toronto Central LHIN is interested in expanding data collection into the Home and Community Care sector.

In line with promoting tested and proven strategies, Sinai Health System proposed a one month pilot at Circle of Care, one of the Home and Community Care services providers, as a lead up to LHIN-wide implementation. This approach fits with Sinai Health System's overall strategy of 'starting small' during an initial roll out of patient/client demographic data collection. More importantly, it will shape the Toronto Central LHIN's approach for collecting data across all Home and Community Care settings and provide evidence-based recommendations across the sector.

Circle of Care Pilot Timeline

Task	2018			2019			Notes
	Oct	Nov	Dec	Jan	Feb	Mar	
Data collection areas							
Identify Circle of Care pilot lead							
Identify areas of data collection							
Communication plan for staff and patients							
Identify who is affected/needs to know about the expansion							
Communicate demographic data collection to staff and patients							
Privacy impact assessment							
Develop strategies on storing and viewing demographic data							
IT Systems readiness							
Ensuring IT capability to capture data							Explore IT data collection options: i.e. 1. identify solutions transferable to Service Provider Organization & Care Coordinators, 2. developing reports. For the pilot due to time constraints simply use Excel
Development of IT solution to pull data							
Planning for accessibility to data through patient chart (esp. language)							
Staff training							
Identify data collectors who need to be trained							
Schedule training sessions (with MSH or independently)							

Circle of Care Pilot Timeline

Task	2018			2019			Notes
	Oct	Nov	Dec	Jan	Feb	Mar	
Embed Data Collection into Operations							
Identify process for addressing patient feedback/concerns							Currently Patient Relations contact information on brochure and website which needs to be updated. Communicating and messaging is an ongoing process.
Embed practices on assessing demographic data quality							
Data collection							
target: <u>75%</u> (minimum 75%)							
Report on Pilot Findings							

Data Collection in Home and Community Care: Proposed Pilot at Circle of Care



Set up the Groundwork

- Meet Leadership / assign pilot lead
- Establish: collection population, target and data collectors.
- Select demographic question form
- Establish collection method and finalize workflow
- Adapt materials
- Create data entry document

Meet leadership and assign project lead:

- Aug. 2nd, 2018:
- **Carey Lucki**, CEO, Circle of Care
 - **Melanie de Wit**, VP of Risk & Chief Risk Officer, Sinai Health System
 - **Caroline Bennett-AbuAyyash**, Health Equity Specialist, Sinai Health System
 - **Virginia Duarte Walsh**, Health Equity Specialist, Sinai Health System
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- Dec. 20th, 2018:
- **Carey Lucki**, CEO, Circle of Care
 - **Lara De Sousa**, VP of Client Services, Circle of Care
 - **Dara Zarnett**, Director, Quality, Risk & Process Improvement, Circle of Care
 - **Lily Yang**, Senior Director of Quality & Patient Experience, Sinai Health System
 - **Virginia Duarte Walsh**, Health Equity Specialist, Sinai Health System



Project Lead

Establish population, collection target, and data collectors

Population Clients receiving personal support and homemaking deemed eligible by Toronto Central LHIN Home and Community Care

Target At least 75% of clients (returning and new) that are seen within a one month period in Toronto Central LHIN funded Home and Community Care programs/services at Circle of Care.

Collectors Volunteers: - Client Service Supervisors
- Intake Workers
- Case Managers
- Social Workers
- Professional Practice Leaders

Select Demographic Question Form

There are 2 types of demographic question forms. One for CHC and one for Hospitals. They vary in the two following questions:

CHC

5. What is your gender? Check ONE only

- 1. Female
- 2. Intersex
- 3. Male
- 4. Trans - Female to Male
- 5. Trans - Male to Female
- 6. Two-Spirit
- 7. Other (Please specify): _____
- 98. Do not know
- 99. Prefer not to answer

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

- 1. \$0 - \$14,999
- 2. \$15,000 – \$19,999
- 3. \$20,000 – \$24,999
- 4. \$25,000 – \$29,999
- 5. \$30,000 – \$34,999
- 6. \$35,000 – \$39,999
- 7. \$40,000 – \$59,999
- 8. \$60,000 or more
- 98. Do not know
- 99. Prefer not to answer

Hospital

5. What is your gender? Check ONE only

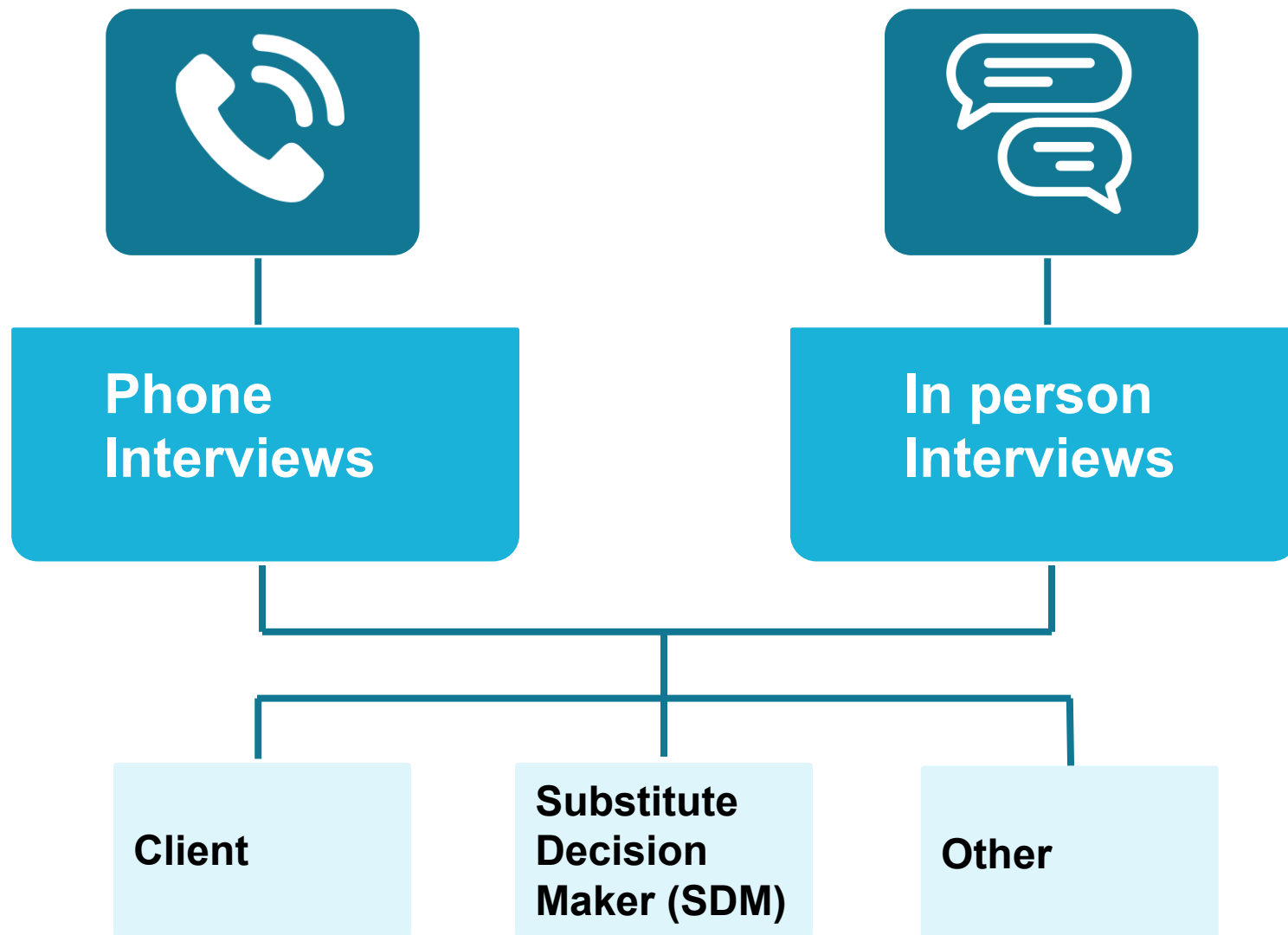
- 1. Female
- 2. Intersex
- 3. Male
- 4. Trans - Female to Male
- 5. Trans - Male to Female
- 6. Other (Please specify): _____
- 88. Prefer not to answer
- 99. Do not know

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

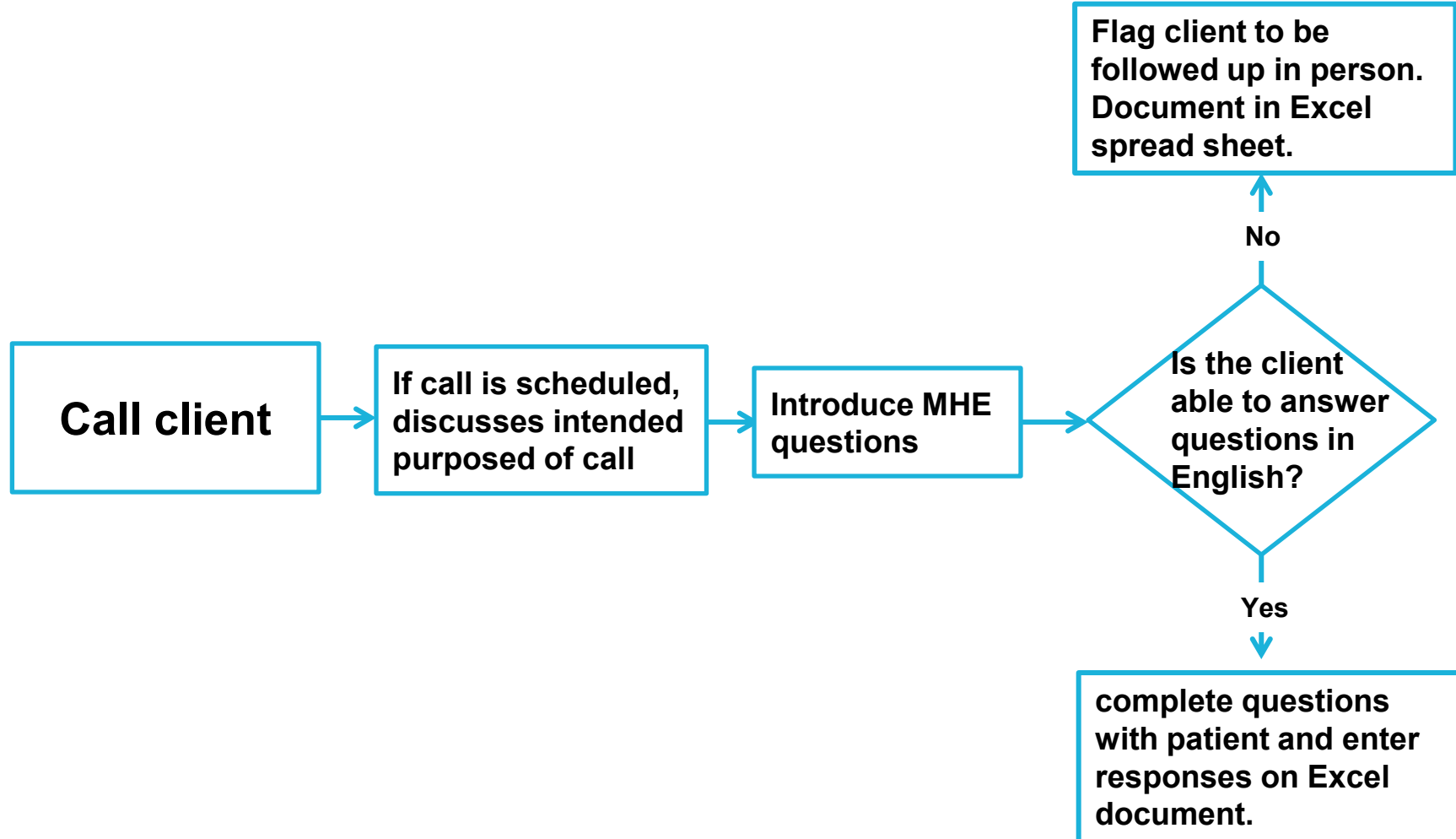
- 1. \$0 - \$29,999
- 2. \$30,000 – \$59,999
- 3. \$60,000 – \$89,999
- 4. \$90,000 – \$119,999
- 5. \$120,000 – \$149,999
- 6. \$150,000 or more
- 88. Prefer not to answer
- 99. Do not know

Circle of Care Pilot

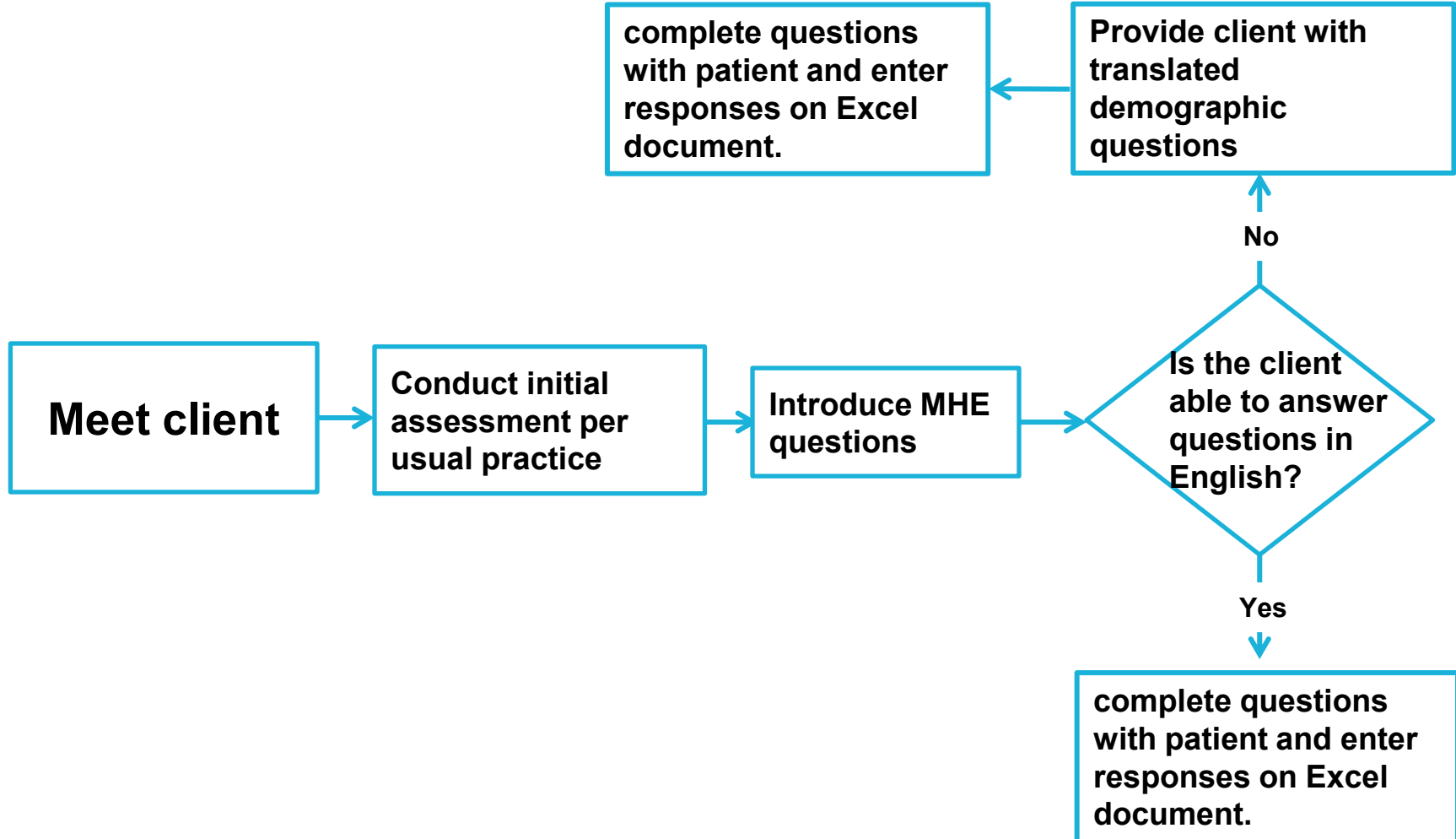
Establish Data Collection Method



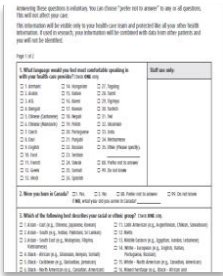
Finalize Workflow – Phone Interview



Finalize Workflow – in-person Interview



Measuring Health Equity Client Materials



Demographic Questions

- Standardized form
- Available in English, French, Arabic, Chinese, Hungarian, Italian, Korean, Portuguese, Russian, Spanish, Tamil, Vietnamese



We ask because we care
Collecting demographic information in health care



Brochure

- Help patients understand why we ask the demographic questions
- Available in English, French, Arabic, Chinese, Hungarian, Italian, Korean, Portuguese, Russian, Spanish, Tamil, Vietnamese



Poster

- A poster for patient engagement around demographic data collection.

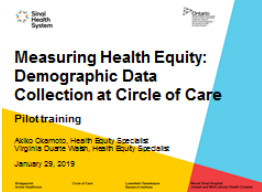


Plain Language Glossary

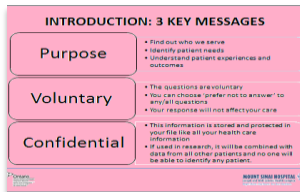
- Provides plain language definitions of key terms used on the demographic question form

Materials Adapted for Circle of Care pilot

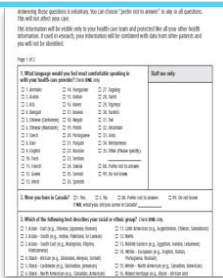
Due to time constraints only the following materials were adapted:



Training Presentation (See Appendix B)



Cheat Sheet (See Appendix C). Further adapted by Dara Zarnett (See Appendix C-1)



Introduction of English Demographic Question (See Appendix D)

Data Entering Document (See Appendix E)

Excel document

- Client ID Number
- Date of Birth
- Postal Code
- Encounter Type
- Follow-up to Phone Interview
- Visit Type
- Encounter Date
- Bypass Questions
- Language of Demographic Questions
- Respondent
- 8 Demographic Questions
- Data Collector
- Position
- Notes

Concerns raised during setting up the groundwork

Concern	Response
<p>Privacy concern regarding having client's personal information linked to demographic question responses on Excel Spread Sheet</p>	<p>Given that: it is a pilot, collection is only one month worth of data, and Excel is being used rather than a secure EMR, it was decided to remove personal identifiers from clients and assign them a number in Excel document. This decision was made with the acknowledgement that this would limit our ability to use the data beyond creating client profile summaries. Additionally, in the recommendation section of the report end-users engagement will be recommended to ensure that actual privacy concerns are addressed.</p>

Concerns raised during setting up the groundwork

Concern	Response
<p>Privacy concern regarding having staff access client's charts who are not part of their circle of care, and who otherwise don't have reason to be in the chart.</p>	<p>Under PHIPA, a custodian is permitted to use personal health information for the purpose of activities to improve the quality of care or to improve or maintain the quality of any related programs or services of the custodian.</p>

Concerns raised during setting up the groundwork

Concern	Response
<p>Income question – household income may vary as what the income was last year may not be applicable to the client’s current situation. For instance, if a client’s spouse passes away, their household income may be significantly lower than when they lived with a spouse.</p> <p>Additionally, a client may not be aware of their household income as they may be supported by family members.</p>	<p>For the pilot, income question will be kept as is. This being said, in the recommendation section of the report we will suggest this question be revised to capture the client’s situation more accurately. We need to ensure the data reflects what we are trying to achieve by collecting this data.</p>

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Educate staff

- Data collecting and entering training

Training (1/2)

Dates

- January 31st, 2019 – 6 participants
 - February 1st, 2019 – 19 participants
-

Participants

- 25 Participants:
- 2 Directors
 - 4 Client Service Supervisors
 - 3 Intake Workers
 - 8 Case Managers
 - 4 Social Workers
 - 1 Social Work Placement Student
 - 1 Community Coordinator
 - 2 Professional Practice Leaders

Training (2/2)

Content

- Understanding Health Equity
- The mandated TC LHIN Health Equity Questions
- Demographic Data Collection:
 - Best practices
 - Overcoming Data Collection Challenges
 - Data Collection at Circle of Care
- Data Entering
- Data Quality
- Resources and Materials
- Role Playing Scenarios

Training Packages

- 2 Hour Power Point Presentation
- Training Manual
- Demographic Questions
- Brochure
- Cheat Sheet
- Glossary of Terms
- Training Evaluation
- Patient Feedback Questionnaire

Training Feedback

Of 25 participants, **19 staff completed the training evaluation form.**

Feedback was as follows:

- **18** participants found the training **helpful**. Of these, **11** found it **very helpful**.
 - Background information, addressing client's concerns, role playing, explanation of gender and race question, cheat sheets, scripts, video, and brochures were highlighted to be most helpful.
- **15** participants found the facilitators performance **excellent** and **4** found the performance **good**.
- **14** participants reported **feeling prepared** to carry out data collection. Of these, **3** reported feeling **very prepared**. The remaining **5** participants reported feeling **somewhat prepared**.
 - When asked what could be improved in the training, it was noted that it would be helpful to have more scenarios, have the opportunity to watch a scenario between interviewer and client prior to role playing, and have a short break during the training.

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Roll out 1 month data collection

- Make all staff resources available
- Share patient communication materials

Data Collection

Period February 11th, 2019 to March 8th, 2019

- Materials**
- 30 hardcopy demographic question forms
 - 20 laminated translated demographic question forms
 - Individual data entering spread sheets
 - 50 Measuring Health Equity brochures
 - 20 laminated Measuring Health Equity brochures
 - 3 Measuring Health Equity posters
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Data Collection in Home and Community Care: Proposed Pilot at Circle of Care



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Roll out 1 month data collection

- Make all staff resources available
- Share patient communication materials
- Check-in with staff

Evaluate & Report

- Compile data
- Summarize data
- Staff evaluations
- Record client's feedback
- Overall findings of the pilot
- Recommendations
- Limitations

Compile Data

Between February 11th and March 8th, 2019 Circle of Care saw 608 Toronto Central LHIN clients*. Of these, 149 clients were approached. Those who were not approached were due to the following reasons:

- Understaffing. Of the 25 trained staff members, 6 staff could not participate in data collection. One staff was due to personal reasons and the other 5 due to unexpected staffing changes.
- Clients could not be reached (contacted multiple times with no answer, hospitalized, and on vacation).
- Clients were deemed not survey capable by phone due to the following reasons** :
 - cognitive and hearing impairments, and
 - language barrier.

*excludes 19 clients who were considered clients but during that month the clients were either deceased, discharged, or placed in Long Term Care prior to demographic questions being asked.

**This point raises concerns of the accuracy of the data summaries reflecting the actual Toronto Central LHIN client population that received services at Circle of Care during this 1 month period and the ability of the data to accurately identify health disparities. This will be addressed in more detail further on.

Compile Data

Of the 149 clients that were approached, **123 clients responded the demographic questions.** Making the:

- organizational participation rate: **20.2%**
- participation rate among those clients who were approached: **82.5%**

Those clients that were approached and refused to answer were due to the following reason:

- clients did not understand the questions,
- caregiver refused to answer,
- no time during encounter,
- language barrier, and
- clients mistrusted the phone call.

Compile Data

As noted previously, **19** staff were responsible for demographic data collection:

- 5 case managers
- 2 client service supervisors
- 3 intake workers
- 1 professional practice lead
- 7 social workers
- 1 student

The overall participation rate was very high ranging from 70% to 94.7%, with the highest rate among client service supervisors.

Although data collectors were offered many alternatives to data collection methods, data was collected through two specific methods:

- In-person interviews
- Unscheduled phone interviews

Compile Data

In person interviews:

- All in person interviews were conducted by a client service supervisor during scheduled recurring visits.
- Ten clients were asked the demographic questions. **9 clients provided demographic data information** (90% participation rate).
- All questions were asked using the English demographic question form.

Unscheduled phone interviews:

- One hundred and thirty-nine clients were approached through unscheduled phone calls (i.e. only contacted for the purpose of asking demographic questions). Of these, **114 clients provided demographic data information** (82.0% participation rate)
- Ninety-nine respondents were clients, 26 were substitute decision makers (SDMs), and 12 were other (caregivers, spouse and children).
- Participation rate was higher among SDMs (96.1%) compared to clients (79.2%) and others (75%).
- One hundred and nine clients were asked using the English question form while five clients were asked using the Russian question form.

Compile Data

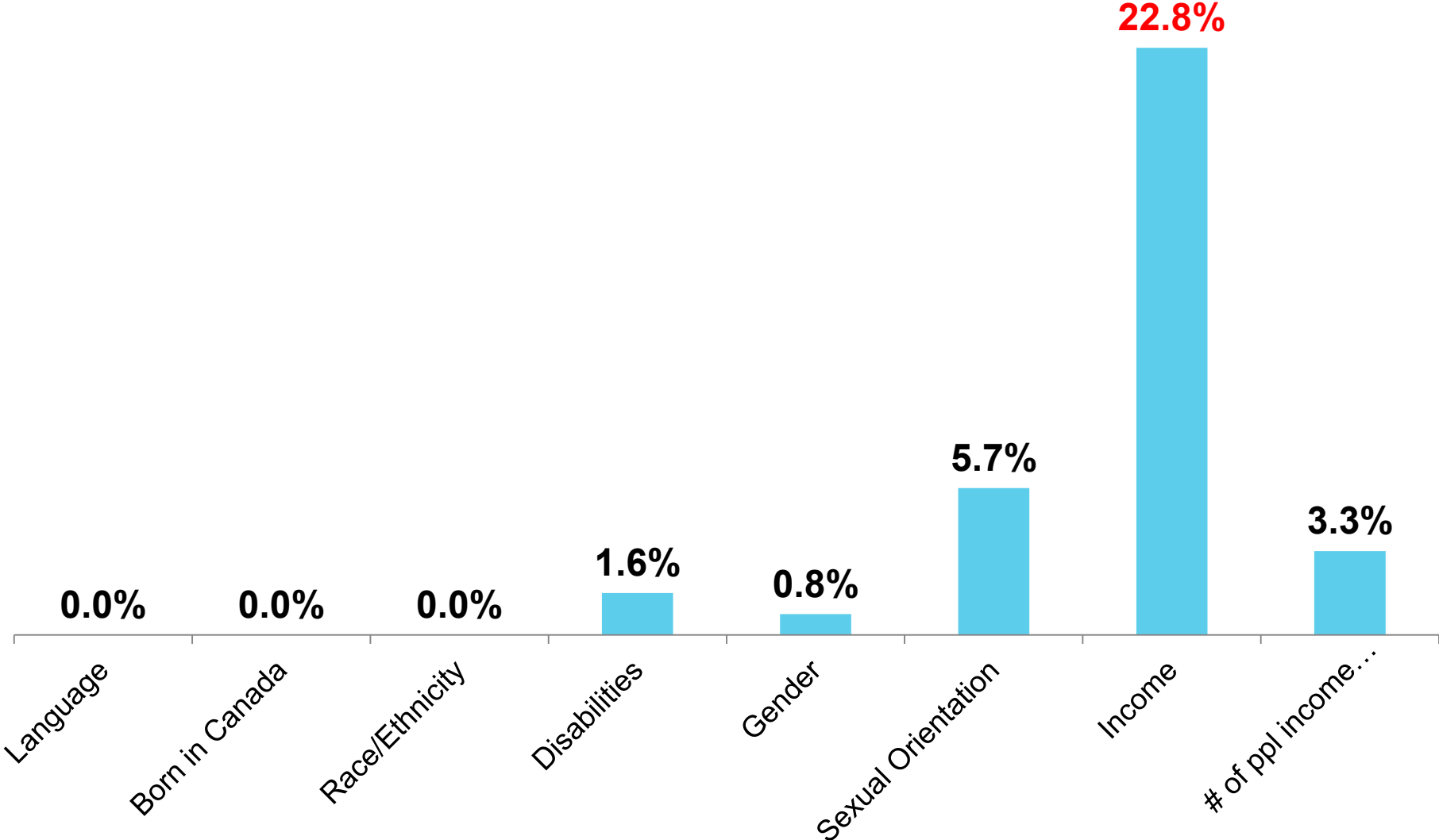
Overall, the data quality among those clients that were approached and participated was excellent* with 'prefer not to answer', 'do not know', and 'missing data' rates below the 10% target for most questions.

- **Prefer not to answer (PNA)** rates ranged from **0.0%** language, 'born in Canada, and race/ethnicity to **22.8%** for income.
- **Do not know (DNK)** rates ranged from **0.0%** language, 'born in Canada, and gender to **10.6%** for income.
- **Missing** rates ranged from **1.6%** language to **26.4%** for number of people income supports.

A breakdown of the rates per question are seen in the following 3 graphs.

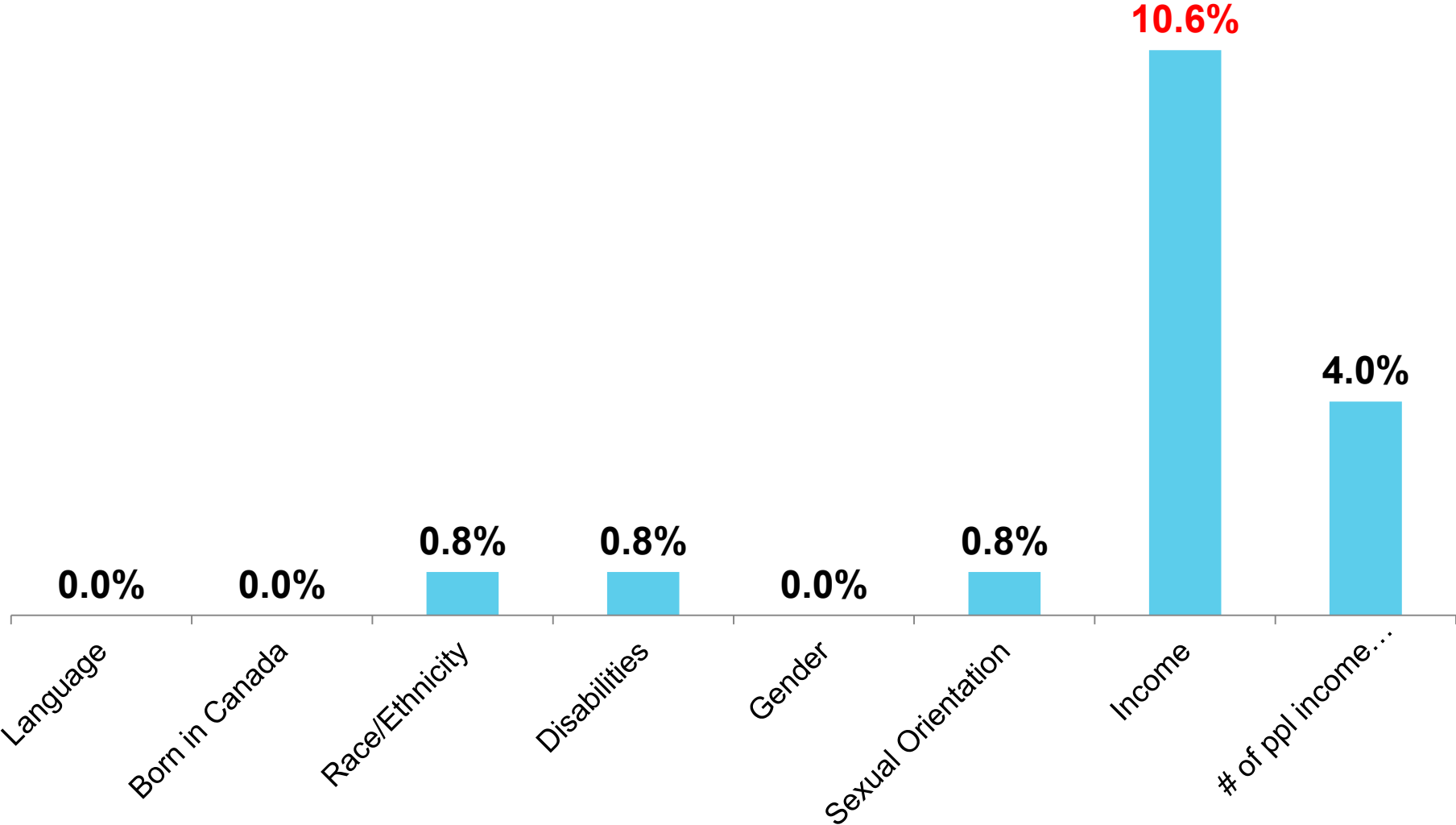
Compile Data

Prefer Not to Answer' Rate per Question



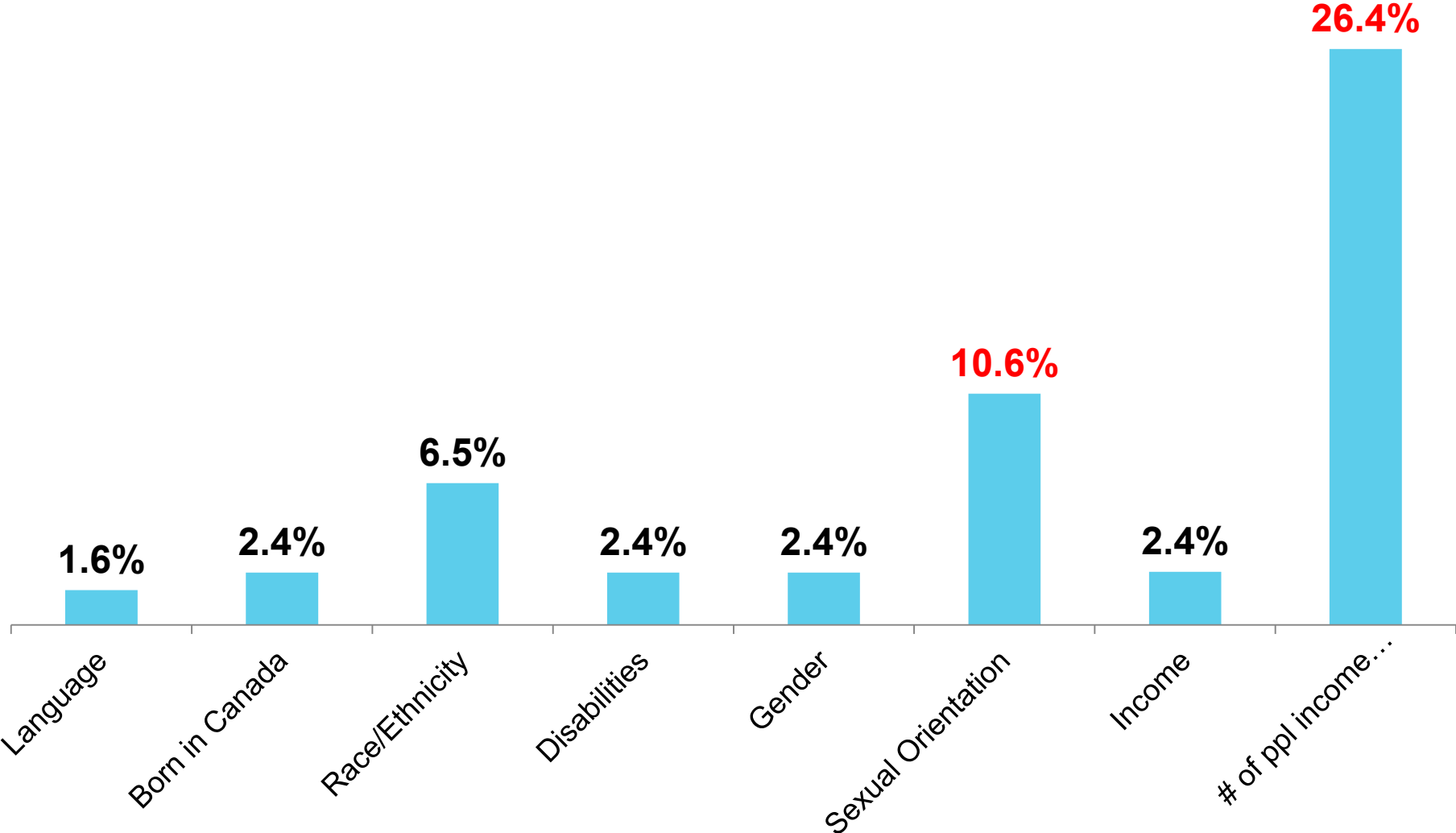
Compile Data

Do Not Know' Rate per Question



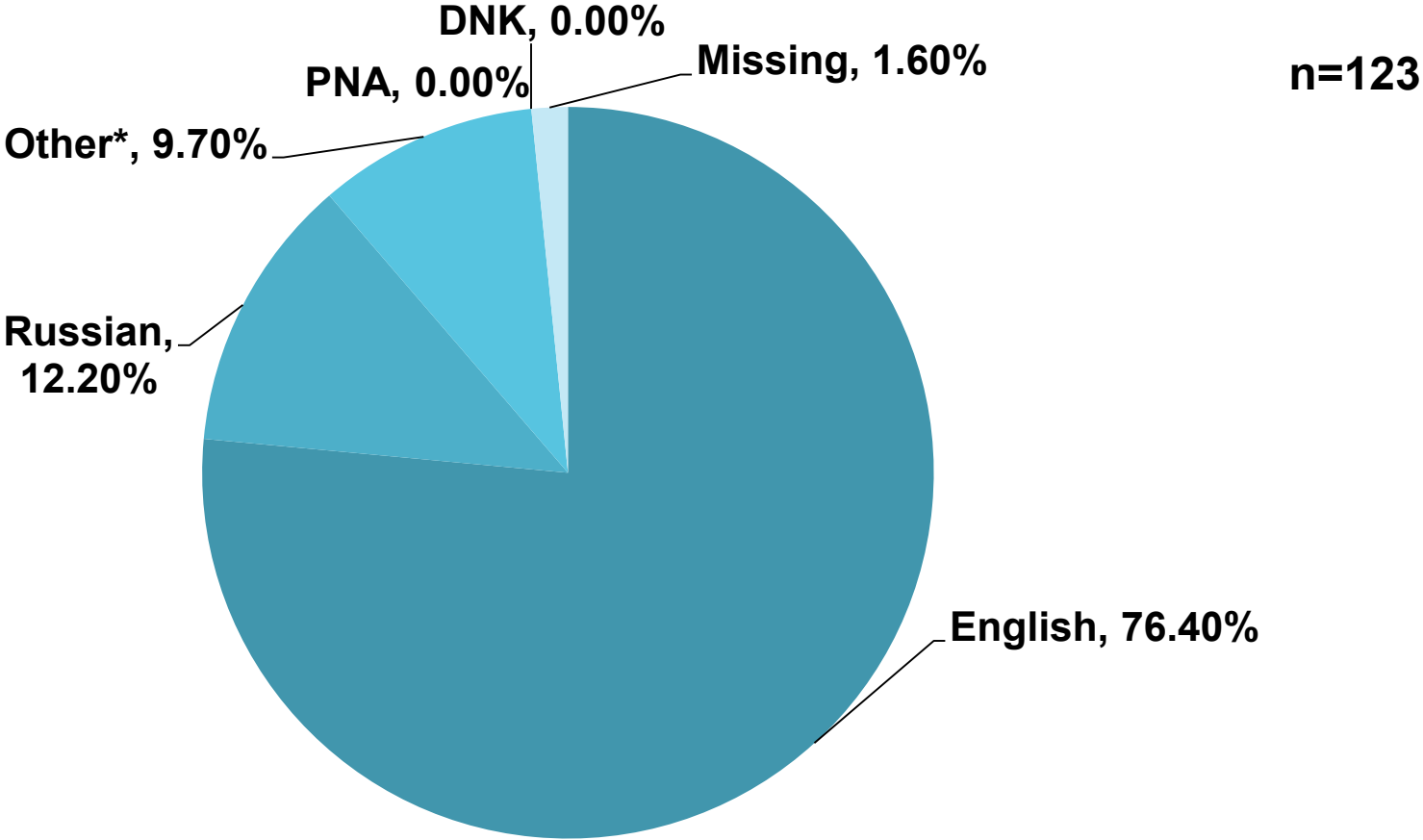
Compile Data

Missing Data' Rate per Question



Summarize Data

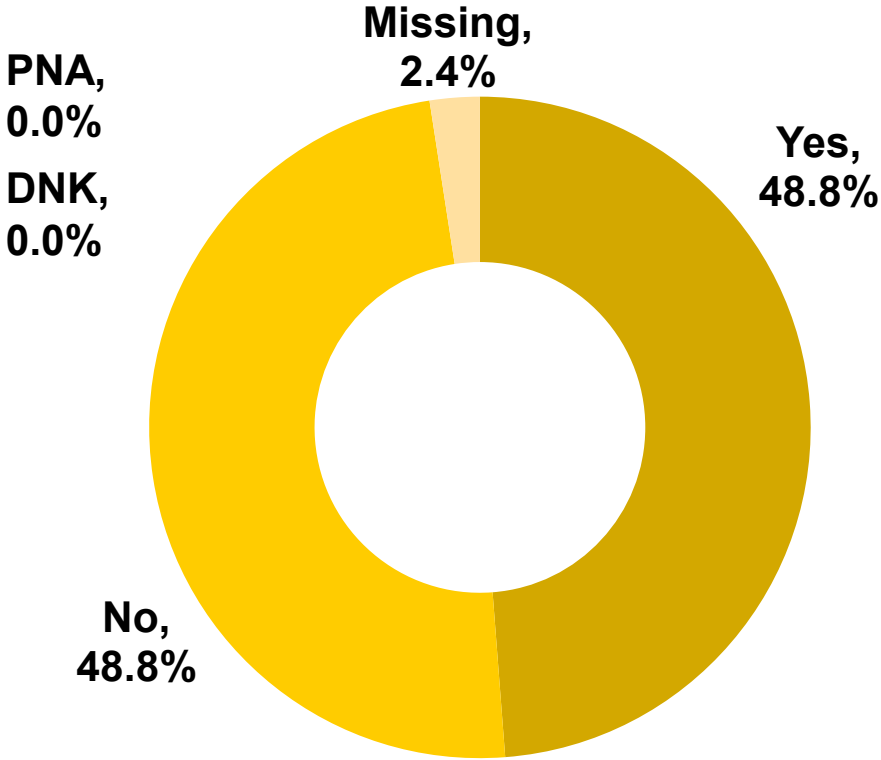
What language would you feel most comfortable speaking in with your health-care provider?



*Other: Italian (1.6%), Tamil (1.6%), Mandarin (0.8%), Hungarian (0.8%), Polish (0.8%), Spanish (0.8%), Tagalog (0.8%), Other (2.4%).

Summarize Data

Were you born in Canada?



n=123

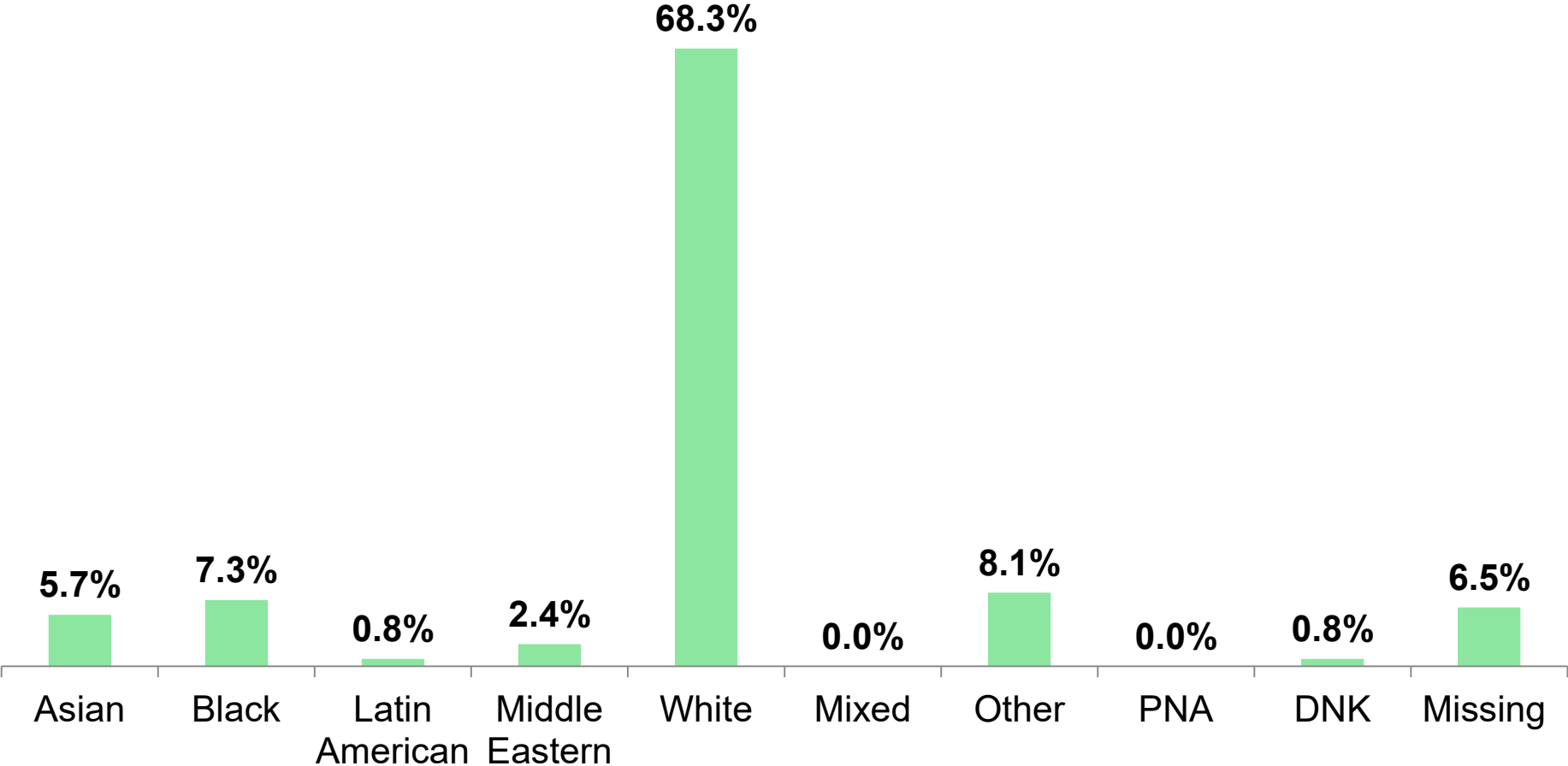
n=60

YR arrival in Canada	Responses (%)
Before 2008	65.1%
2008 – 2013	0.0%
2014 – 2019	76.7%
Missing	21.7%

Summarize Data

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

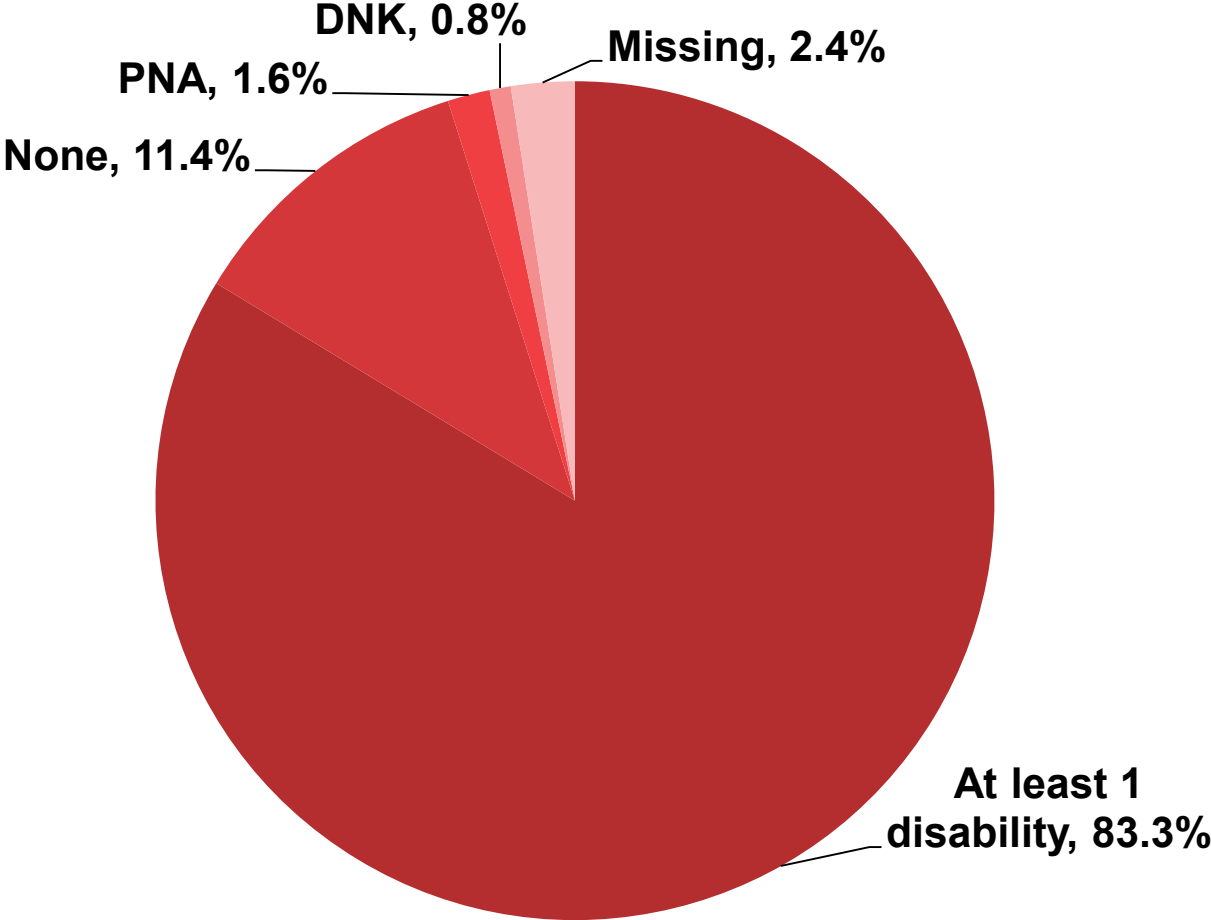
n=123



Summarize Data

Do you have any of the following (disabilities)?

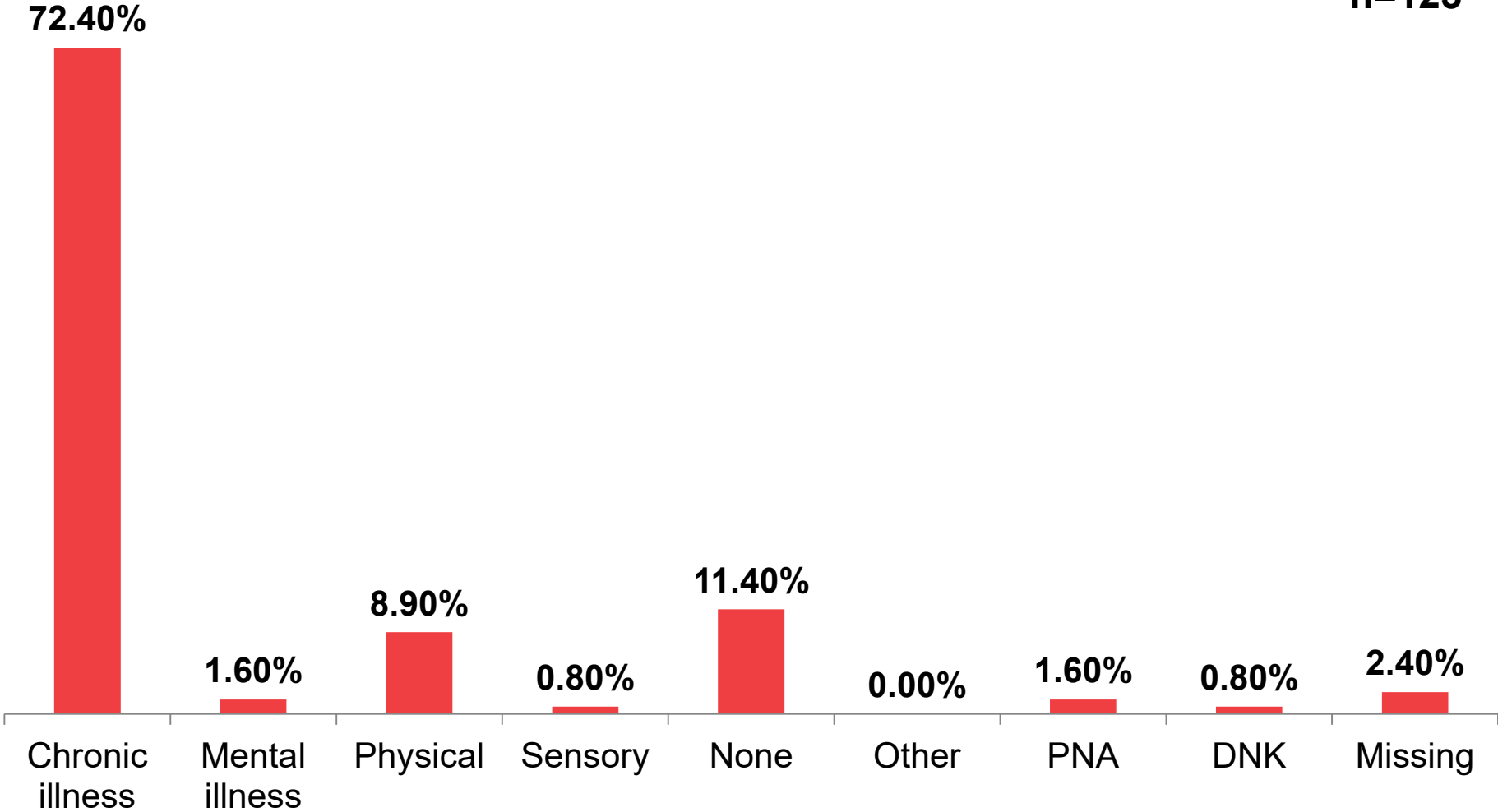
n=123



Summarize Data

Do you have any of the following (disabilities)?

n=123

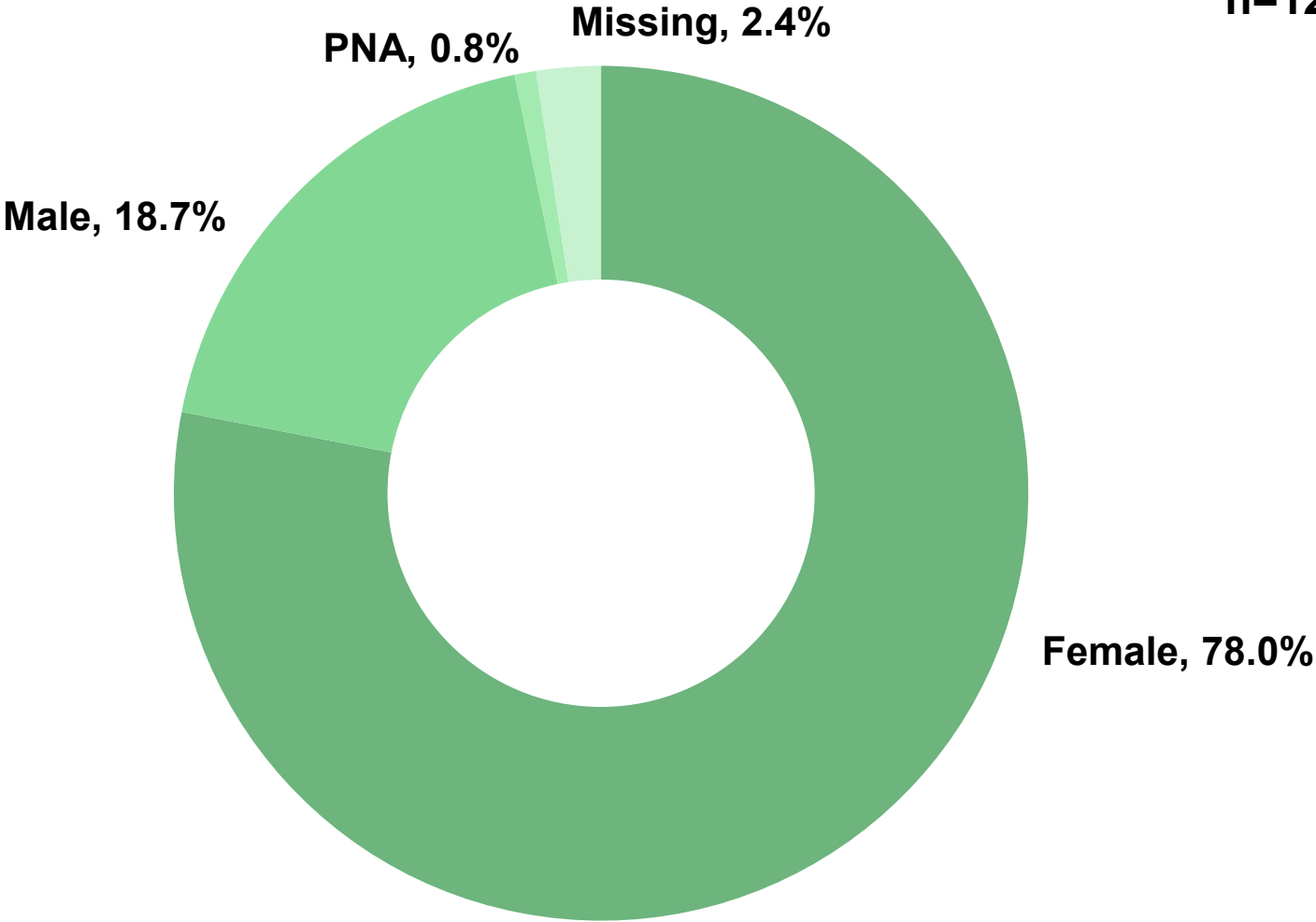


Summarize Data

What is your gender?

n=123

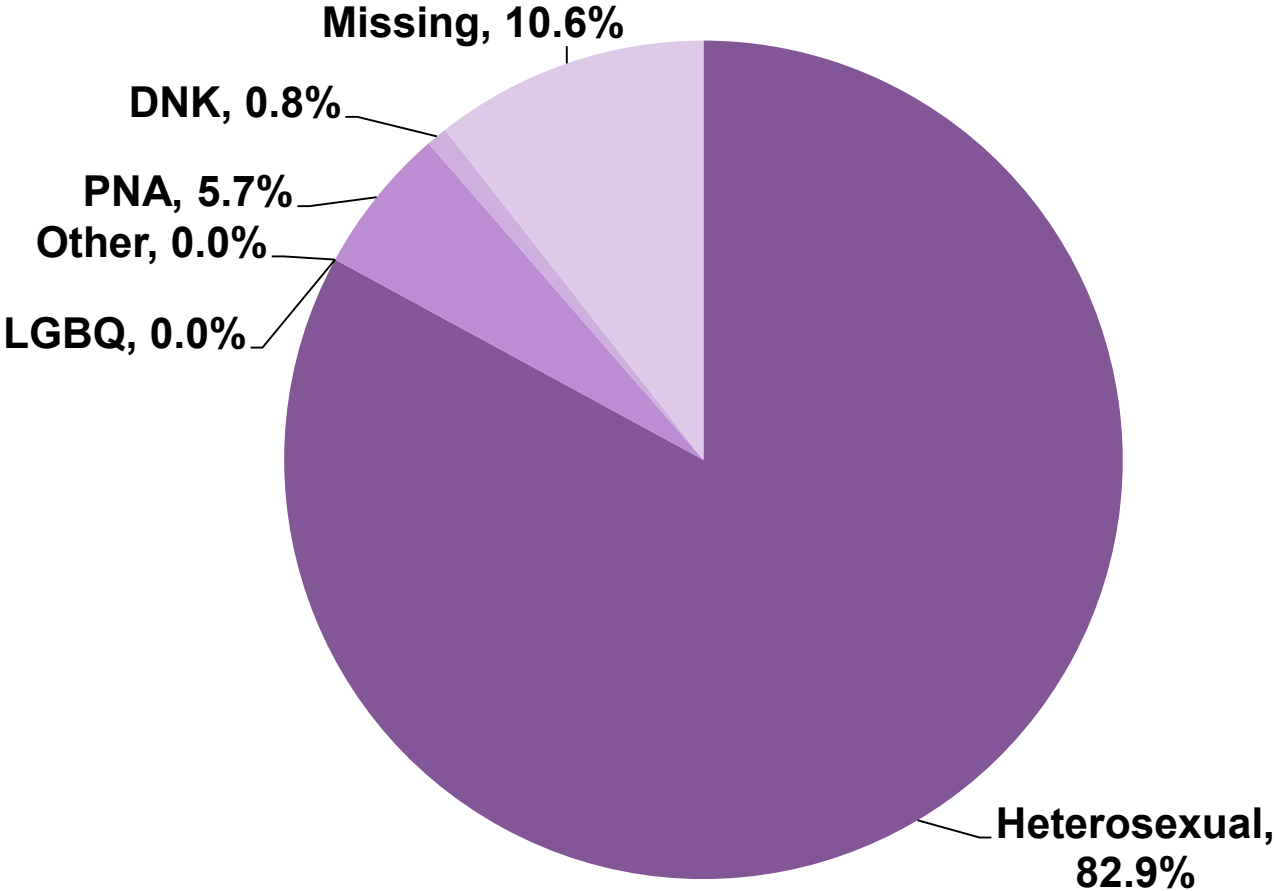
- Intersex, 0.0%
- Trans, 0.0%
- Other, 0.0%
- DNK, 0.0%



Summarize Data

What is your sexual orientation?

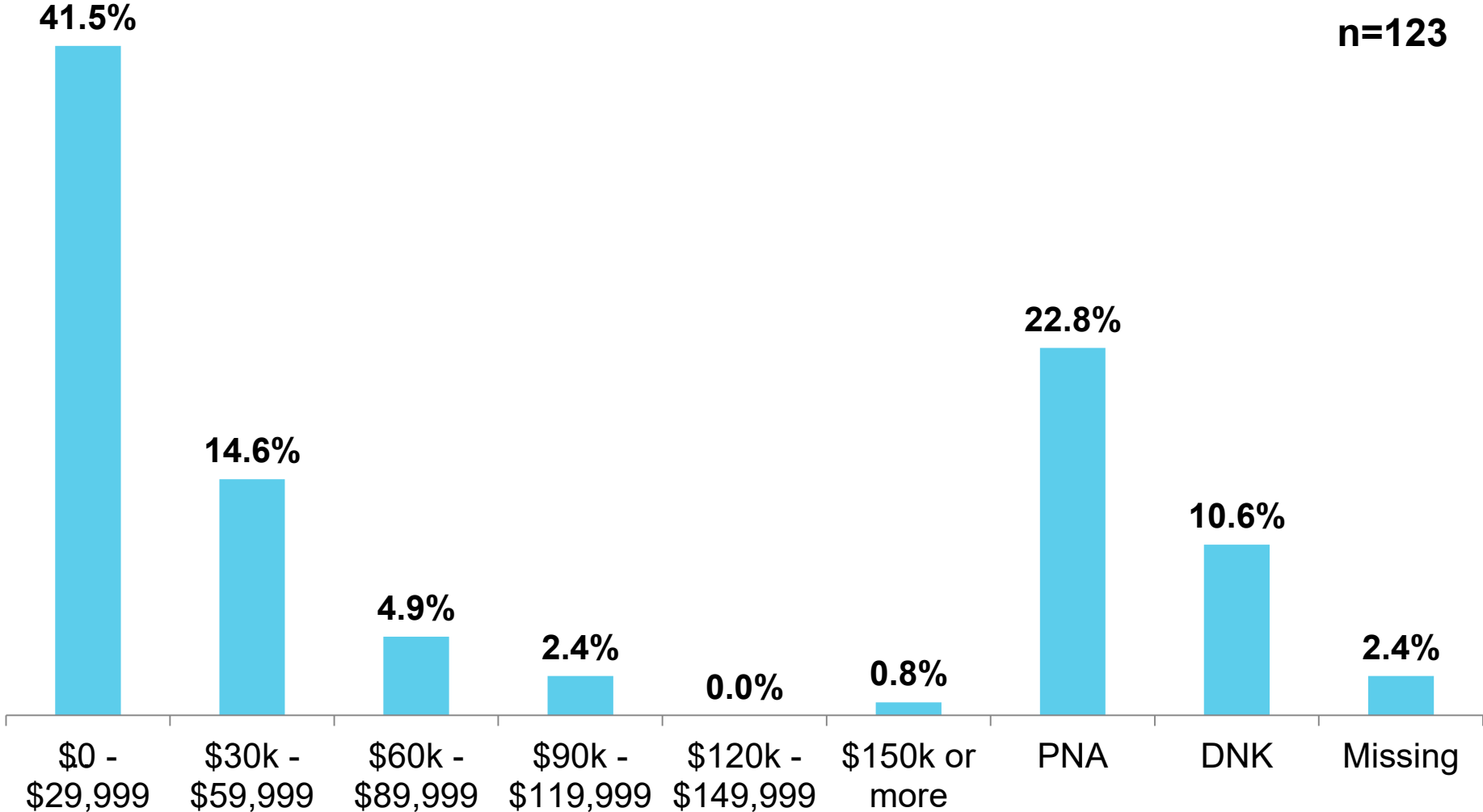
n=123



Summarize Data

What was your total family income before taxes last year?

n=123

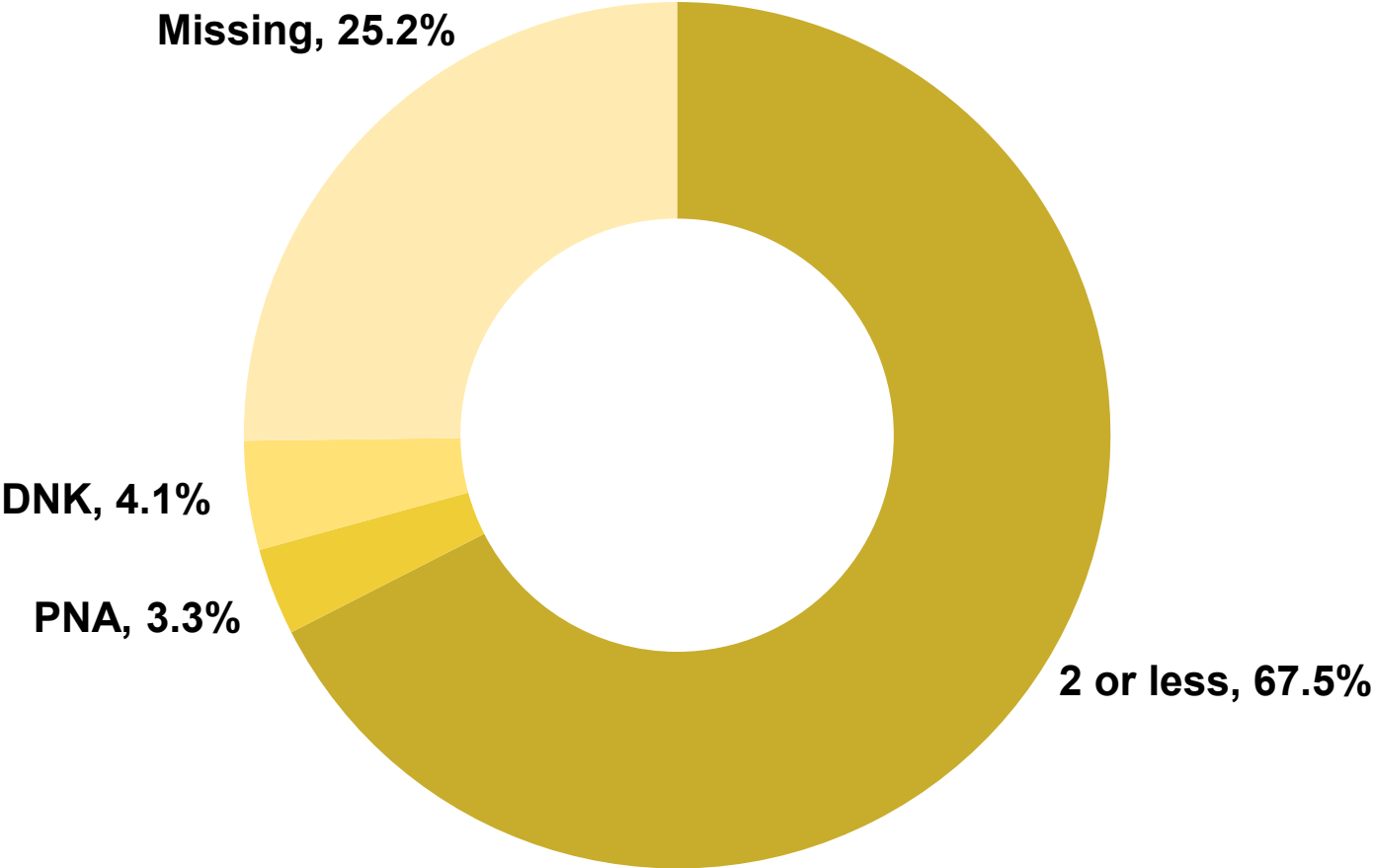


Summarize Data

How many people does your income support

n=123

3 to 4,
0.0%
5 to 7,
0.0%
8 or more,
0.0%



Average number of people
income supports: 1.3

Summarize Data

Diversity Snapshot*



22.3% of clients reported preferring to speak with their healthcare provider in a language other than English



50.0% of clients reported being born outside Canada. Of these, **97.8%** landed prior to 2008



26.3% of clients indicated a non-White race/ethnicity



87.2% of clients reported having at least one disability



80.6% of clients identified as Female and **0.0%** identified as Trans or Intersex



0.0% of clients identified as LGBTQ



64.5% of patients reported making under \$30k, followed by **22.7%** of patients reporting a yearly income of 30k-60k

*reported percentages exclude 'missing, prefer not to answer, do not know' responses in the sample

Staff Evaluations

Purpose To capture the experiences of staff collecting data

Method Anonymous survey on Survey Monkey

Target All staff who participated in the pilot project

Period March 7th to March 15th , 2019

Overview

- Of the 19 data collection staff, 6 completed the staff experience survey. They included 4 social workers, 1 case manager, and 1 client service supervisor.
- All 6 staff completed in-person training facilitated by Sinai Health Equity Team.
- All 6 staff collected demographic data by phone interview.

Staff Evaluations

Feedback

- 2 staff found the administration of demographic questions slightly uncomfortable, 1 staff found it neutral, 2 staff found it comfortable, and 1 staff found it very comfortable.
- Of the 8 demographic questions, 4 staff felt uncomfortable discussing sexual orientation, 1 felt uncomfortable discussing income, and 1 felt comfortable discussing all questions.
- In terms of staff experience collecting data it was noted:
 - most clients had no issues providing demographic information,
 - clients were uncomfortable providing personal information over the phone,
 - older clients (90+) had difficulty understanding questions regarding sexual orientation and gender, and
 - it was challenging to engage senior clients with cognitive and hearing impairments over the phone.

Client Evaluations

Purpose To capture the experiences of clients being asked demographic questions

Method Voluntary and anonymous paper form survey immediately after data collection

Target Each staff was asked to complete 2 client surveys.

Period February 11th, 2019 to March 8th, 2019

Overview - Of the 19 data collection staff, only 1 staff was able to conduct client experience survey.

Client Evaluations

Feedback

- 2 Circle of Care clients completed the survey immediately after demographic data collection by phone.
- 1 client strongly agreed, and 1 client agreed that the information was collected in an appropriate format.
- Both clients confirmed that the staff explained the purpose of the data collection.
- Both clients confirmed that they were informed this survey was confidential and voluntary.

Overall Findings of the Pilot

The Circle of Care pilot identified key findings for the roll-out of demographic data collection across the Home and Community Care sector in the Toronto Central LHIN. These key findings involved various successes and challenges.

Successes:



Home and Community Care clients are open and willing to answer the Toronto Central LHIN demographic questions.

Although the overall organizational participation rate was low due to many clients being excluded, the overall participation rate among those clients who were approached was high (surpassing the desired target of 75%). Furthermore, the data quality was excellent with most of the questions ‘prefer not to answer’, ‘do not know’, and ‘missing data’ rates well below the 10% target.

This high participation rate and good quality data was seen regardless of collection method, who asked the questions, and who answered the questions (client vs. SDM or other). This finding was in line with the “We ask because we care” hospital pilot and Measuring Health Equity CHC pilot.

Overall Findings of the Pilot - Successes



Leadership involvement is key in facilitating demographic data collection.

From the initial phase of the pilot at Circle of Care leadership was engaged and involved. Dara Zarnett, Director, Quality, Risk & Process Improvement, was the assigned project lead. Dara ensured that: all key staff were informed, reviewed workflows, scheduled trainings, ensured all data collection and data entering materials were appropriate for the setting, participated in trainings, and compiled data. Without the constant involvement of Dara, Sinai Health System's Health Equity team would not have been able to rollout the pilot within the allotted time frame.

Additionally, Dara's presence during training ensured staff concern's regarding demographic data collection were heard and addressed. This ensured staff's willingness to participate in this project even though participation was voluntary.

Overall Findings of the Pilot - Successes



Training provided necessary preparation for staff to collect demographic data.

Evidence from the pilots conducted at hospitals and CHCs indicated that ‘how you ask’ can be more important than ‘what you ask’. Thus, the training that was provided to Circle of Care staff collecting data included a significant portion of: exploring why each question was asked, learning best practices in asking the questions, and opportunity to practice asking these questions.

Of the 25 staff that were trained, only one staff decided to not participate due to religious beliefs. The other 5 staff who participated in the training but did not collect data was due to reasons beyond their control.

Given the high participation rate among those clients who were approached, the quality of data, the post-training evaluation, and the post-pilot survey, we can infer that the training was effective. The only two questions which staff reported feeling uncomfortable with during the training and post-training was sexual orientation and household income (which was consistent with findings from previous pilots). This staff discomfort may have attributed to the slightly higher ‘missing data’ rate for sexual orientation as well as higher ‘prefer not to answer’ and ‘do not know’ rates for household income.

Overall Findings of the Pilot - Challenges

Challenges:



Client Feedback

During the pilot, staff were provided with client feedback surveys (See Appendix F). Staff were requested to select two clients with whom they had collected information from to obtain their feedback on the experience. Unfortunately, only 1 staff conducted the client feedback survey. The reasons provided for not being able to conduct client survey varied including that the opportunity did not feel right to ask additional questions, staff felt uncomfortable taking up more time, or staff forgot.

Furthermore, due to time constraints and limited staff, it was not possible to conduct independent client surveys which could have provided a more accurate picture of client's experiences among those who were willing to participate and those who refused to participate.

Overall Findings of the Pilot - Challenges



Contacting clients and demographic data collection via phone interviews

As noted previously, a large number of Toronto Central LHIN Home and Community Care clients were not approached to answer the demographic questions due to various reasons: deemed not survey capable, could not be reached, cognitive and hearing impairments, and language barriers.

Although in the originally designed workflow staff conducting phone interviews were instructed to flag for in person follow up with clients who could not answer the questions via the phone, last minute staffing issues and short duration of the pilot prevented this step from occurring. Thus, it is important to emphasize that opportunities do exist to address these issues such as: having interpreters available for the phone interviews, follow up in person, or mail in the question form or brochure prior to conducting the calls.

Another challenge when conducting phone interviews was that it was difficult to ensure that all staff were reading all available answer options found in the Toronto Central LHIN demographic question form. This raises concerns on the accuracy of the data captured particularly for questions regarding gender and sexual orientation where 0.0% of the clients identified as being part of the LGBTQI2S population.

Overall Findings of the Pilot - Challenges



Treating demographic questions as a survey rather than additional medical information required to provide care.

Although since the start of the pilot it was emphasized that the mandated demographic questions were not a survey nor questionnaire but additional information required to provide equitable care, it seemed that staff had difficulty viewing the questions this way. This raised two specific challenges:

1. Initially several staff raised concerns that these questions were intrusive. These concerns were addressed during the training. It was emphasized that the demographic questions were equivalent to any other medical information.
2. In some cases, SDMs were not contacted on behalf of clients who were deemed incapable because Circle of Care saw it necessary that all clients provide consent prior to contacting SDMs for the demographic questions. However, this consent was not needed. Demographic data can be provided by whoever already has permission to speak on the client's behalf. This being said, given that this was a short term pilot, Circle of Care's decision was respected. In the future, if the demographic questions were implemented at a larger scale, this step would not have to occur as questions would be part of the general assessment process. Questions would be directed to whoever the assessment was being done with.

Overall Findings of the Pilot - Challenges



Data entering in Excel document

Given the limited time allotted to conducting this pilot, there was no opportunity to explore how to integrate the demographic question into the clients' EMR at Circle of Care. Thus, all staff entered data in individual Excel documents which were then compiled by the project lead. This, as previously discussed, raised the privacy concern regarding having client's personal information available on the Excel spread sheet. Thus, all personally identifiable information was removed from the Excel sheet, and the data was not linked to clients' EMRs. As a result, beyond creating client summaries the data was un-linkable to other data points.

Recommendations



Communication and Engagement

1. As illustrated in this and previous pilots, the involvement of senior leadership is imperative in ensuring staff engagement and the seamless implementation of data collection in the initial stage.
2. Demographic data collection should not be perceived as a survey or research questionnaire. It should rather be recognized as a component of health care information by both staff and clients.
3. Introduce health equity as an organizational priority in order to increase staff engagement and commitment.
4. Share with client communication materials as well as have staff discuss with clients why demographic data collection is important, how the demographic data information is going to be used, and emphasize that participation is voluntary and prefer not to answer is always a viable answer option.

Recommendations



Data Collection Procedures and Workflow

1. Both in-person and phone interviews were found to be effective methods of data collection based on the results from this pilot. Having said this, there is a need for organizations to create strategies to increase participation amongst clients with cognitive/ speech / sensory impairments, and clients with language barriers. Examples of such strategies include: in-person visits, having interpreters available for phone interviews, and mailing translated demographic questions or brochures prior to conducting the phone interviews.
2. If conducting phone interviews, it is critically important to read out all answer options for all questions but particularly for the gender, sexual orientation and income questions in order to ensure the data accurately reflects the client population being served.

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Recommendations



Data Collection Procedures and Workflow (continued)

3. It is highly recommended to conduct periodical client experience surveys to ensure that clients' feedback is incorporated in staff training and project evaluation. It is particularly important to capture the perspectives of clients who were screened out from data collection and deemed not capable. Where possible, an independent audit of data collection is ideal in capturing the experiences of clients who face these barriers.
4. In order to ensure high and consistent data quality, conducting data audits on a regular basis and follow up trainings are recommended.

Recommendations



Staff Training

1. Provide initial in person Measuring Health Equity demographic data collection training developed by Sinai Health System, which can be adapted by each organizations (See Appendix B). This training should include at least 15 minutes to practice asking the questions.
2. Data entering training should be provided in order to ensure data is entered correctly. If data is not entered correctly, the data cannot be used at a future point which would defeat the purpose of collection.
3. Project leads should work with their teams to ensure appropriate time is allotted for in person training and that all staff who will be collecting and entering data will be present during the training.
4. In addition to the Measuring Health Equity demographic data collection training, “Are You An Ally” training can be used to increase staff comfort in collecting demographic data. Furthermore, this training will teach staff how to ask difficult questions. The training presentation can be downloaded from <http://www.torontohealthequity.ca>

Recommendations



IT Solutions

1. Demographic data must be handled in accordance with PHIPA. It should be stored in a secure and protected system with all other personal health information.
2. Demographic data must be linked with clients' EMRs in order to allow organizations to use the data in a way beyond client profile summaries.
3. To ensure high data quality, use a data entering system which is capable of conducting automated data quality reports or facilitates regular data audits.
4. Identify ways in which the IT system that stores demographic data allows for the information to be shared with SPOs and other LHINs when clients are referred / transferred. Furthermore, explore ways in which demographic data across organizations can be pooled and accessed between organizations collecting data.
5. There are opportunities to explore alternative technology solutions for efficient data collection such as mobile tools, tablets, or e-portals to name a few.

Limitations to the Pilot

- 1. Minimal client feedback** was obtained due to staff not conducting client feedback surveys and the lack of time and resources to conduct an independent audit.
- 2. Limited time allotted to conduct pilot** minimized the ability to test various collection methods. For instance, no data was collected during first home visits, intakes, or pre-scheduled phone calls. Furthermore, it limited the amount of work that could have been conducted with IT in data entering and data use.
- 3. Clients screened prior to being contacted for participation.** Clients who were deemed “survey incapable” were not contacted for data collection. This may have an impact on data quality and skewed the clients profile summary obtained during this 1 month period.

Demographic Data Collection at Home and Community Care Toronto Central LHIN



Overview:

In order to build an evidence-based model for data collection in Home and Community Care, Sinai Health System consulted with key leads at Home and Community Care Toronto Central LHIN.

The purpose of these consultations were to assess the applicability of the demographic data collection model identified in the Circle of Care pilot to demographic data collection conducted by Toronto Central LHIN Care Coordinators.

1st Meeting with H&CC Toronto Central LHIN Leadership

Date February 19th, 2019

Participants **Toronto Central LHIN:**

- **MayLin Poon**, Client Services Manager – Intake and Referral
- **Wilfred Cheung**, Director – Sub-Region planning
- **Nancy Kraetschmer**, Director – Privacy and Risk,
- **Daniel Litvack**, Manager – Business Intelligence
- **Daniel Altenberg**, Manager – Business Intelligence
- **Ian Gibson**, Manager – Adult Supportive Care
- **Cynthia Damba**, Manager, Health Analytics
- **Yasmin Kassam**, Senior Policy Advisor

Circle of Care:

- **Dara Zarnett**, Director, Quality, Risk & Process Improvement

Sinai Health System:

- **Virginia Duarte Walsh**, Health Equity Specialist
- **Akiko Okamoto**, Health Equity Specialist

1st Meeting with H&CC Toronto Central LHIN Leadership

Agenda

1. Introduce the Measuring Health Equity project;
2. Update on Circle of Care Pilot; and
3. Hear from meeting participants on:
 - Home and Community Care Toronto Central LHIN Structure (identify: potential steering committee, lead, areas of data collection, staff who need to know about the project, staff who would be collecting/entering data, workflows);
 - Patient privacy (concerns regarding patient privacy and potential paper form data collection, will data be shared with SPOs; how will data be shared with SPOs; who will address patient concerns); and
 - IT (what would be used to collect and store demographic data, how will data quality be tracked).

1st Meeting with H&CC Toronto Central LHIN Leadership

Key Discussion Point Summary

- Consensus that this is a worthy initiative for Home and Community Care.
- Training should not stop with how to collect data but provide training to staff on how to specifically work with marginalized populations such as trans populations.
- Circle of care is contacting all clients prior to contacting SDM. Consensus that this is a good practice as having SDMs does not mean that clients are incapable. At times, listed SMDs are not legitimate SDMs.
- The IMIT group at TC-LHIN should be included in the conversation as Excel is not sustainable for data collection beyond the pilot.
- H&CC has been collecting language, gender and income information. May not be as detailed as the Toronto Central demographic question. Worth exploring overlapping questions in order to conduct data mining rather than asking questions twice.

1st Meeting with H&CC Toronto Central LHIN Leadership

Key Discussion Point Summary

- Concerns raised that there is potential of missing our homeless population. How would we ensure that we are capturing their information?
- May be challenging to collect data during initial visit as clients go through 110 questions in RAI assessment. May be worth considering collecting this information in following visits.
- Ideally this information will be shared with SPOs.
- An initial target of 75% may be hard to achieve initially but possible after a year or so.
- Worth looking into using Client and Caregiver Experience Evaluation survey to collect demographic data. It's an easy system that you can add questions to.
- Staged roll out of demographic data collection would be ideal.

1st Meeting with H&CC Toronto Central LHIN Leadership

Next Steps

- Toronto Central-LHIN to determine if and how to roll out demographic data collection in Home and Community Care setting. Some initial steps to consider:
 - Form home and community care health equity working group
 - Establish initial roll-out areas and potential workflow
 - Meet with IMIT to establish best data entering, storage, and extraction method

Acknowledgement

The Sinai Health System Health Equity Team gratefully acknowledges the Circle of Care senior leaders and volunteer data collection staff for their strong commitment and enthusiasms in the promotion of health equity within our health care system. We are especially grateful for the project lead Dara Zarnett, Director, Quality, Risk & Process Improvement at Circle of Care, who ensured the successful implementation of this pilot project by communicating with staff, reviewing all materials, compiling the data, and coordinating with Health Equity Team. We would also like to express our gratitude towards Cynthia Damba and Yasmin Kassam from Toronto Central LHIN for their direction and support.

Contact Information

- For more information on the support available from Sinai Health System, please contact:

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- Visit www.torontohealthequity.ca

Appendices

See separately attached documents

- Appendix A** Toronto Central LHIN Hospital and CHC demographic questions
- Appendix B** Circle of Care adapted demographic data collection training power point presentation
- Appendix C** Cheat Sheet
- Appendix C-1** Further Adapted Cheat Sheet by Dara Zarnett
- Appendix D** Circle of Care adapted demographic data questions
- Appendix E** Circle of Care demographic data entering Excel spread sheet
- Appendix F** Client Feedback Survey