

TC LHIN CHC Demographic Data Collection of Children & Youth

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Collecting demographic data for children and youth in CHCs

The CHC Evaluation Framework does not include guidelines for how to capture socio-demographic data from clients under the age of 18. The *Measuring Health Equity in TC LHIN Community Health Centres Pilot Project* identified issues and gaps in collecting demographic information of children and youth. Guidance around how to ask younger populations under 18 came up at a number of CHCs. More specifically, staff expressed:

- A need for policy on how to collect demographic data from children/babies, particularly on sexual orientation.
- A need for a tool for collecting data from all clients under 18.

The following recommendations on how to collect demographic data from children and youth at TC LHIN CHCs have been informed by the following:

- Planned Parenthood has a long-established practice of collecting client demographic data starting at 13 years old
- The importance of standardizing pediatric data collection practices across hospitals and CHCs.
- IT systems in CHCs do not have the capacity to accommodate two sets of demographic questions (e.g. one for adults and for one for youth).
- The vast amount of literature documenting the discrimination, possible abuse, and potential for expulsion from the home that LGBTQ youth experience when children come out to their caregivers.

Recommendations:

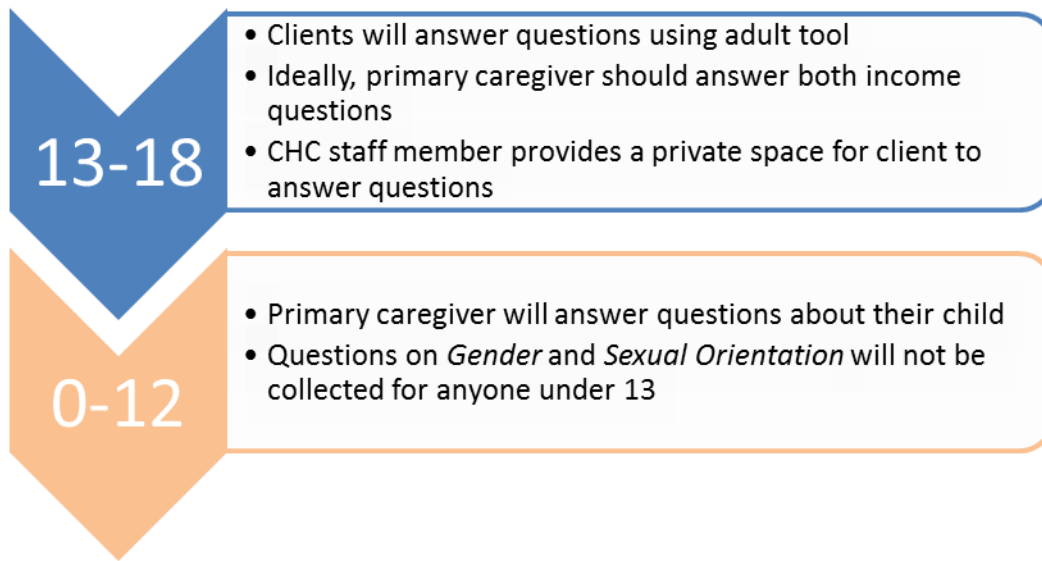
Recommendation 1: For all clients 13 years of age and older, TC LHIN demographic questions will be asked directly from the client using the adult tool.

Recommendation 2: For clients under the age of 13 years, their primary caregiver will answer questions about their child using the adult tool with the exception that questions on *gender* and *sexual orientation* will not be collected.

Additional Considerations

- CHC staff members provide a private space for clients 13 years and over to answer questions without their caregiver present.
- If the client does not know the answers to the two income questions, CHC staff obtain data from primary caregiver whenever possible.
- CHCs further explore NOD and BIRT's capacity to link client files between family members to complete missing data (income questions in particular).

Summary of Collecting Demographic Data of Children and Youth in TC LHIN CHCs



Background

The Hospital for Sick Children and Holland Bloorview Kid's Rehab Hospital completed a pilot project on the collection of demographic data with pediatric populations in September 2014. The pilot project examined the adaptation of the eight TC LHIN demographic questions and made recommendations on how to collect demographic data from youth and children.

SickKids and Holland Bloorview used evidence-based methods to determine:

- The age of applicability for some variables (sexual orientation, gender identity)
- Who should answer the questions (child, primary caregiver(s), both)

The findings of their pilot project included the following recommendations primarily directed at hospitals collecting pediatric demographic data:

- For patients 14 years and older, the primary caregiver will be asked to respond to the two income questions. Then the primary caregiver will be asked to leave and the patient will fill out a demographic form in private for questions on language, born in Canada, racial/ethnic group, disabilities, gender and sexual orientation. The youth demographic tool also included slight variations from the adult tool:
 - The sexual orientation question was slightly modified from the adult question.
 - The gender and sexual orientation answer options include additional answer options.
- For patients under the age of 14, the primary caregiver will be asked to answer demographic questions about themselves using the eight TC LHIN questions plus an additional core question on the education of the caregiver. The primary caregiver will also be asked to respond to four demographic questions about their child – language, born in Canada, racial or ethnic group and disabilities ONLY.

- They did not include the questions on gender and sexual orientation for patients under 14 years of age because at that age, the caregivers are completing the questions for their child. They were concerned that by asking caregivers these questions, they may be encouraging a conversation about the patients' gender and/or sexual identity that may not be ready to occur. Given the vast amount of literature documenting the discrimination, possible abuse, and potential for expulsion from the home that lesbian, gay, bisexual, trans and queer (LGBTQ) youth experience when they come out to their caregivers, they felt that including these two questions in the pediatric tool had the potential to cause harm to the patient.