

CARE Data Collection

Frequently Asked Questions (FAQs)

April 2024

General Questions – Patients

Question	Response
<i>What is CARE data?</i>	<p>CARE Data stands for Collecting Accurate and Robust Equity Data. When we ask you about your CARE data, we are asking you to tell us about demographic factors that describe you and your circumstances, such as your race, ethnicity and preferred language.</p> <p>The information you provide is confidential, and only accessible to your doctor or members of your care team. Collecting CARE data will help us better understand the needs of our patient populations in an effort to improve quality and provide patient-centric care. We ask because we CARE, but providing your CARE data is optional.</p>
<i>Why is HHS collecting CARE data?</i>	<p>Every person has the fundamental right to be treated fairly and equitably. Collecting CARE Data (such race, ethnicity and language) will help us to better understand our patients in order to provide more culturally and socio-demographically informed care and mitigate disparities in patient experience and quality of care.</p>
<i>How is my CARE data going to be used?</i>	<p>We can use CARE data to understand how factors like social determinants of health (e.g., race, ethnicity, language) are linked to health outcomes in order to make changes that improve the health of all patients. If used in research, your information will be combined with data from all other patients and no identifying features, such as your name, will be included.</p> <p>With your permission, your health care team will use your CARE data to help refer you to services (e.g., interpretation services, treatment programs), give you information, or identify any unique needs (e.g., accommodations for disabilities).</p>
<i>What are social determinants of health?</i>	<p>Social determinants of health are non-medical factors that can influence health outcomes, such as income and social status, employment and working conditions, education and literacy, childhood experiences, housing and physical environments, access to health care, gender, culture, race, and social supports. They are the conditions in which people are born, grow, work, live, and age, and include the wider set of forces and systems shaping the conditions of daily life.</p>
<i>What is the difference between equity and equality?</i>	<p>Equality means giving each individual or group the same resources or opportunities, regardless of their needs or circumstances.</p> <p>Equity recognizes that each person or group has different circumstances, and gives them the resources or opportunities they need to reach an equal outcome. This is different than equality, where individuals or groups are given the same resources and treatment regardless of their needs.</p> <p>As an example, <i>equality</i> means giving everyone a pair of shoes, whereas <i>equity</i> means giving everyone a pair of shoes that fit.</p>
<i>What is health equity?</i>	<p>Health equity means striving for the highest standard of health outcomes for <i>all</i> people, while taking into account that some people are at a higher risk of illness and disease, based on things like their race, age, income level and/or gender identity. This means striving for fairness in things like access to health care, and providing additional supports for people who benefit most from them when they are ill or trying to prevent illness.</p>

What is the difference between race and ethnicity?

Race refers to groups of people based on shared physical traits, such as skin color, hair type, and facial features. *For example, Black, Latin American, South Asian, East Asian, Middle Eastern, Arab or West Asian, Southeast Asian, White, etc.*

Ethnicity refers to a person's cultural identity, which includes shared customs, traditions, language, and often a common heritage. It's how people identify with a particular group that has a shared cultural background.

Ethnicity is related to language, religion, and ancestry but is not the same as nationality or citizenship.

For example, Chinese, East Indian, English, Filipino, French, German, Irish, Italian, Jamaican, Jewish, etc.

What if I identify with more than one category for race and ethnicity?

When providing your information to the registration clerk and self-disclosing via MyChart, you have the option to select multiple choices for both race and ethnicity.

Do I have to participate in CARE data collection?

No. Your participation is completely voluntary. You can answer "prefer not to answer" to any or all questions. Choosing not to share your data with us will not impact the care you receive at HHS.

Why are you asking these specific questions?

We chose these questions based on research and the experience of other health organizations that have similar initiatives in place to support quality and equitable care. By asking these questions, we can better understand who our patients are and improve how we provide care and services. Also, sometimes people experience discrimination in health care settings. We want to make sure that is not happening at HHS, and if it is, we want to correct that.

Do other hospitals ask these questions?

Yes, HHS is one of many hospitals across Canada to collect this type of demographic information, some hospitals having started in 2013.

Will you share my data with other hospitals?

Your demographic information is like any other information on your health record.

We only share your health information with other health care providers when it is required in order for you to receive care. For example, if you visit an emergency department at another centre, they may ask us to send them your HHS medical record so that they can understand your health history and make informed decisions about your care. To ensure continuity of care, some demographic information is sent to mandatory provincial repositories.

HHS follows all patient privacy laws and your health information is fully protected by the highest level of data security.

Is it legal to ask me these questions?

Yes. In fact, the Ontario Human Rights Code encourages the collection of this kind of data when the purpose is to stop discrimination and promote equity.

I'm only here for a quick appointment. How is this relevant to my care?

It's important for us to know who we serve. By collecting this information from everyone who walks through our doors, we gain a better understanding of where we need to make improvements to our care and services. Your participation is completely optional and choosing not to participate will not impact the care you receive

Who can I talk to if I have more questions?

For more information please speak to your health care provider or visit <http://hamiltonhealthsciences.ca/CAREdata>

Privacy and Personal Health Information Questions

Question	Response
<i>How is CARE data stored and for how long?</i>	CARE data will be stored as part of your health record. For adults, this information will be retained for at least 10 years from the date of the last entry. For children, this data will be stored for at least 10 years after the day on which they reach 18 years of age. Changes and additions made through MyChart will update your health record accordingly.
<i>Who will be able to see my CARE data?</i>	<p>The information is treated with the same level of confidentiality as the rest of your personal health information. Only health care professionals and hospital staff within your circle of care are authorized to access your CARE data.</p> <p>Limited exceptions include if you consent to participate in a research study, or if a non-HHS provider requests your health record in order to inform your care with them (e.g., your family physician, or another hospital).</p> <p>Sometimes, we share a patient's information with a non-HHS provider if it's required in order for you to receive care. For example, if you visit an emergency department at another centre, they may ask us to send them your HHS medical record so that they can understand your health history and make informed decisions about your care.</p>
<i>Can I update, remove or change my data?</i>	<p>Yes, you can update, remove or change your data at any time in MyChart, or by speaking to your health care provider or a business clerk when you visit one of our sites.</p> <p>Visit our website for more information about how to get MyChart.</p>
<i>Who can I contact if I have privacy questions?</i>	For more information about health care information privacy, please visit our website , email privacy@hhsc.ca or call 905-521-2100 ext. 75122.