

Memorandum

To: Marylin Kanee,
Director of Human Rights & Health Equity
Department

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From: Amanda Brennan,
Corporate Privacy Officer and Freedom of
Information Coordinator

Ext.: 416-586-4800
Ext. 2101

Subject: Measuring Health Equity: Collecting Socio-Demographic Patient Data

INTRODUCTION

This memorandum describes the Measuring Health Equity Initiative and how the personal health information collected by the Initiative can be collected, used and disclosed.

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PROJECT BACKGROUND

The Toronto Central Local Health Integration Network (TC LHIN) has consistently identified the achievement of equitable outcomes as a core component of quality care, and has reflected its commitment to equity through including “equitable access” in its most recent strategic plan.

The TC LHIN conducted a consultation in May 2011 with 44 participants representing various health networks, health service providers and community health partners on the priorities that should drive the TC LHIN’s Equity Action Plan. During that consultation, the collection of equity socio-demographic variables in hospitals was identified as a top equity priority.

The Human Rights and Health Equity Office at Mount Sinai Hospital participated in a research project, entitled the “Tri-Hospital plus Toronto Public Health Data Collection Pilot Project” (the “Tri-Hospital+”), which focused on developing and implementing a demographic data collection plan in Toronto Public Health and several Toronto hospitals, namely Mount Sinai Hospital, St. Michael’s Hospital and the Centre for Addiction and Mental Health.

Given the TC LHIN’s commitment to equity and Mount Sinai Hospital’s experience with demographic data collection in hospitals, the TC LHIN has asked Mount Sinai Hospital to lead the standardized collection of patient-level socio-demographic data across its hospitals. Furthermore, the TC LHIN has mandated patient-level demographic data collection in hospitals, with March 31, 2013 as the deadline for the initial implementation of demographic data collection.

PROJECT GOAL

It is the goal of the “Measuring Health Equity: Collecting Socio-Demographic Patient Data” Initiative, to support the implementation of a program at all TC LHIN hospitals whereby the hospital collects patient demographic information in order to gain a better understanding of the patient population that they serve, and to then enable hospitals to provide better care and to plan and deliver better programs which will promote health equity¹.

Mount Sinai Hospital will support TC LHIN hospitals in:

1. Developing a model for gathering patient-level demographic information;
2. Implementing a pilot on the collection of patient-level socio-demographic data by March 31, 2012; and

¹ “Health Equity” can be defined as ensuring quality care regardless of race, religion, language, income or any other individual characteristic.

3. Planning for the application of demographic data toward health equity and quality.

Mount Sinai Hospital Support

As part of its leadership role in implementing this Initiative, Mount Sinai Hospital will assist other TC LHIN hospital committees by:

- Developing and disseminating communication tools explaining to staff and patients the rationale for collecting patient information;
- Disseminating evidence linking health equity to quality of care and the results of the research study on collecting this data;
- Keeping TC LHIN hospitals up-to-date on leading research and best practices in the area of demographic data collection and its application toward health equity;
- Providing support and materials by:
 - creating a tool for the collection of socio-demographic patient data based on the research and based on an environmental scan of best practices,
 - sharing results of the research study to assist hospitals in choosing the most effective ways to collect patient information, and
 - assisting hospitals with the selection of indicators and health outcomes to be measured;
- Developing and disseminating materials, including manuals and video clips, to help hospitals train their staff on data collection; and
- Supporting and bringing together IT and decision support groups at TC LHIN hospitals to develop IT solutions that will integrate the collection of socio-demographic patient data into hospital systems.

PROJECT GOVERNANCE

Project Governance within Mount Sinai Hospit

It is Mount Sinai Hospital's recommendation that this Initiative be rolled out within each hospital with a governing committee. At Mount Sinai Hospital, our governing committee includes representatives from:

- Human Rights & Health Equity
- Health Records Services
- Admitting & Registration
- Community Partnerships
- Interpreter Services
- Volunteer Services
- Information Technology
- Privacy/Legal Counsel
- Quality and Performance Measurement
- In-patient Social Workers & Family Health Team Social Workers

As the implementation rolls out, this committee will oversee the data collection, use, retention and disclosure.

In addition, the committee will also oversee all communications that go out to staff and patients about this Initiative, as it is very important that both staff and patients have a clear understanding about what is being asked, why it is being asked and how best to ask.

Project Governance at TC LHIN Hospitals

It is anticipated that TC LHIN hospitals will strike similar committees as they see fit within their clinical environments and with the internal stakeholders they need in order to set up the hospital for successful and sustainable project completion. To support this, Mount Sinai Hospital will work with senior leadership from peer hospitals to facilitate organization-wide engagement for staff and patients.

COLLECTION

The best possible approach for the collection of personal health information² is to have both a legal authority to collect the information and patients' consent to do so. Giving patients the additional option to opt-out of providing information will help further ensure that patients are comfortable and that their privacy rights are respected. As Initiative leaders, Mount Sinai Hospital has prepared a sample pamphlet for patients that explains how their information will be collected, used and potentially disclosed.³

Data Elements

The research conducted by the Tri-Hospital+ suggests that the collection of the following data elements is helpful in determining the patient population that a hospital serves, and how to reduce barriers of access for that population:

- Patients' preferred spoken language;
- Whether or not patients were born in Canada and their year of arrival if applicable;
- Patients' racial background;
- Patients' disabilities;
- Patients' gender;
- Patients' sexual orientation; and

² The data elements collected through the Measuring Health Equity Initiative are considered personal health information, pursuant to the *Personal Health Information Protection Act*, SO 2004, chapter 3, schedule A, because it is proposed that they be retained in patients' hospital chart in identifiable format. Were the data elements to be retained outside of the chart, the information may still be identifiable and therefore subject to the privacy protections in the *Freedom of Information and Protection of Privacy Act*, RSO 1990, chapter F.31; however, if they are not identifiable the data elements would not be subject to the privacy protections of either piece of legislation.

³ Mount Sinai Hospital, "We Ask Because We Care, Answers to Frequently Asked Questions about Patient Demographic Data Collection" Sample Pamphlet.

- Patients’ total family income before taxes and the number of people that income supports.

The Tri-Hospital+ also suggests that patients’ preferred written language, religious or spiritual affiliation and type of housing would be helpful data elements to collect to get a broader picture of health equity; however the collection of these data elements has not been made mandatory by the TC LHIN.

Legal Authority for Collection

All organizations in Ontario are required to abide by the *Human Rights Code*⁴, which “provide[s] for equal rights and opportunities without discrimination”. Discrimination can be overt, but it can also be systemic. Unfortunately, systemic discrimination impacts a greater number of individuals and is more difficult to detect. In order to truly evaluate whether an organization is inclusive, the Ontario Human Rights Commission recommends collecting human rights-based data. In its 2009 report, entitled “Count Me In! Collecting Human Rights-Based Data”, the Commission states that collecting human rights-based data can help organizations:

- Verify, monitor, measure and address gaps, trends, progress and perceptions
- Proactively identify opportunities for improvement and growth
- Attract, retain and motivate diverse, well-qualified people
- Improve the quality of decision-making, service delivery and programming
- Enhance perceptions of being progressive leaders in their sector or industry
- Achieve organizational goals and strategic objectives.⁵

As organizations subject to the *Human Rights Code*, hospitals can look to the spirit of the Code and the recommendations of the Commission as strong support for the Measuring Health Equity Initiative.

Of course, hospitals are not like other organizations subject to the Code; they have additional responsibilities to help carry out the promises of our Canadian health care system. One such promise is accessibility for all. It is so fundamental to our system that accessibility is one of the five criteria⁶ provinces must meet in order to receive federal payments for health care and social services. The *Canada Health Act* codifies these criteria and specifically states:

12. (1) In order to satisfy the criterion respecting accessibility, the health care insurance plan of a province

(a) must provide for insured health services on uniform terms and conditions and on a basis that does not impede or preclude, either directly or indirectly whether by charges made to insured persons *or otherwise, reasonable access to those services by insured persons*;⁷

⁴ RSO 1990, chapter H.19.

⁵ Ontario Human Rights Commission, *Count Me In! Collecting Human Rights-Based Data*, online: <<http://www.ohrc.on.ca/en/count-me-collecting-human-rights-based-data-summary>>.

⁶ *Canada Health Act*, RSC 1985, c C-6, s 7.

⁷ *Ibid*, s 12(1)(a) [emphasis added].

While this legislation establishes the principles of our health care system, legislation directly applicable to hospitals in Ontario further articulates hospitals' specific responsibility to ensure that all patients in Ontario are receiving high quality care.

The *Excellent Care for All Act, 2010* was passed for this reason, to ensure that “all Ontarians, today and tomorrow, can continue to receive high quality health care”⁸ through a “high quality health system ... that is **accessible**, appropriate, effective, efficient, **equitable**, integrated, patient centred, population health focussed and safe”⁹. To this end, ECFAA requires hospitals to survey patients to determine their level of satisfaction with the health care services that they have received:

Surveys

5. (1) Every health care organization shall carry out surveys,

(a) at least once every fiscal year, of persons who have received services from the health care organization in the past 12 months and of caregivers of those persons who had contact with the organization in connection with those services;

...

Purpose of survey

(2) The purpose,

(a) of a survey under clause (1) (a) is to collect information concerning satisfaction with the services provided by the health care organization;¹⁰

This legislation requires¹¹ hospitals to collect information from patients about their experience, and it should apply to the Measuring Health Equity initiative, because the demographic factors (including the eight variables covered in the TC LHIN Mandate) have been consistently proven to be significantly associated with patients' experience of health care and their decision on whether or not to seek out health care services.¹²

This legal authority to collect information from patients about their experience is important because under the *Personal Health Information Protection Act, 2004*¹³, Ontario's patient privacy legislation, hospitals are generally required to seek the consent of a patient to collect personal health information from him or her, unless the hospital is permitted or required by law to collect that information.¹⁴

Patient Consent

⁸ *Excellent Care for All Act, 2010*, SO 2010, chapter 14, preamble [ECFAA].

⁹ *Ibid*, [emphasis added].

¹⁰ *Ibid*, s 5. Under the *Excellent Care for All Act, 2010*, “health care organization” is defined as “a hospital within the meaning of the *Public Hospitals Act*, and any other organization that is provided for in the regulations and that receives public funding”.

¹¹ *Supra* note 10, s 1. While s. 5 does require the collection of patient experience data at least once every fiscal year, there is no prohibition on collecting that data more often.

¹² Mount Sinai Hospital and Ruby Lam CITTA Consultants, *Made in Sinai Health Equity Competencies: Delivering Healthcare to Diverse Communities*, online: <http://www.mountsinai.on.ca/about_us/who-we-are/human-rights/CommunityConsultationMSH.pdf>.

¹³ SO 2004, chapter 3, schedule A [PHIPA].

¹⁴ *Supra* note 13, s. 29(1) and(2).

While the legal authority in ECFAA to collect the information is important, hospitals must be mindful that the demographic data that they will collect is highly sensitive. In some cases, it is the very reason that individuals have received differential treatment. Hospitals must therefore earn patients' trust and confidence. To do so, hospitals should tell patients the purpose for collecting their information and the ways in which the information will be used before asking patients to provide their information. Ensuring that patients are well informed is key to obtaining their consent to collect the information. As Initiative leaders, Mount Sinai Hospital has prepared a sample pamphlet for patients that explains how patients' information will be collected, used and potentially disclosed.¹⁵

Patient Opt-Out Rights

It is also important that patients not feel compelled or coerced to provide the information being asked of them. For this reason, it is recommended that patients are also **informed** told that:

- their participation is voluntary;
- they do not have to complete the questions;
- they can skip items; and
- they can stop at any time.¹⁶

In addition, each question has a box marked "Prefer not to answer", so that patients can decline to consent to the collection of their personal health information. The sample pamphlet prepared by Mount Sinai Hospital, as Initiative leaders, includes detailed information written in plain language about patients' options not to participate.¹⁷

USE

While the Tri-Hospital+ research focused on the collection of data elements solely for the promotion of health equity through program planning, it is anticipated that the data collected through the Measuring Health Equity Initiative will be used to provide health care to the patient, as well as to plan programs to address health inequities and to improve the quality of care for all. A summary of the examples of these anticipated uses has been prepared by Mount Sinai Hospital, as Initiative leaders.¹⁸

Health Care

By collecting the data elements referred to above, it is anticipated that hospitals will be better able to treat their patients because they will be able to provide linguistically and culturally appropriate care. During their stay, hospitals will also be

¹⁵ *Supra* note 3.

¹⁶ See Mount Sinai Hospital and Toronto Central Local Health Integration Network, "Measuring Health Equity in TC LHIN Hospitals News & Updates", January 22, 2013, p 5.

¹⁷ *Supra* note 3.

¹⁸ Mount Sinai Hospital, "Anticipated Uses of Data for Health Care, Program Planning and Quality Improvement" Table.

able to better accommodate patients' unique needs related to disability and gender identity. When planning for discharge, hospitals will be better able to ensure that patients can afford their medications and medical equipment, and if not, create an improved discharge plan and provide additional community support connections for patients.

The information collected from patients can be used in identifiable or aggregate form by the hospital that collected it for the purpose of providing health care¹⁹.

Planning and Delivering Programs

By collecting the data elements referred to above, it is anticipated that hospitals will gain a better understanding of their patient population. This will allow hospitals to better plan programs to promote equal access to care and to address gaps in health equity.

The information collected from patients can be used in identifiable or aggregate form by the hospital that collected it for the purpose of “planning or delivering programs or services that the custodian provides or that the custodian funds in whole or in part, allocating resources to any of them, [or] evaluating any of them”²⁰.

Quality of Care

By collecting the data elements referred to above, it is anticipated that hospitals will be able to analyze aggregate data to identify systemic gaps in the quality of health care received by certain populations. Similar data collected in the United States has helped hospitals identify and ameliorate such gaps, so that all individuals receive the same standard of care, no matter their individual characteristics²¹.

In addition, Measuring Health Equity data will help hospitals to improve patients' accommodations during their care experience and their overall access to care because individuals who feel comfortable in hospitals are more likely to seek out health care services when needed, rather than waiting until their condition requires emergency care. By providing an inclusive environment for all, patients will be better able to navigate the health care system.

The information collected from patients can be used in identifiable or aggregate form by the hospital that collected it for the purpose of “activities to improve or maintain the quality of care or to improve or maintain the quality of any related programs or services of the custodian”²².

DISCLOSURE

¹⁹ *Supra* note 13, s 37(1)(a).

²⁰ *Supra* note 13, s 37(1)(c).

²¹ For example, see work by Dr. Joseph Betancourt, Massachusetts General Hospital, online: <<http://www2.massgeneral.org/disparitiessolutions/staff/betancourt.htm>>.

²² *Supra* note 13, s 37(1)(d).

De-identified and Aggregate Disclosure

Provided that the information is de-identified²³ or in aggregate form, such that no individual patient can reasonably be identified, the health equity data can be disclosed to other organizations that will use it for the purpose for which it was collected or a consistent purpose²⁴.

Identifiable Disclosure

The TC LHIN has made reference to the value of the Measuring Health Equity data for system-wide program planning²⁵. As with the Tri-Hospital+ research, the TC LHIN has found that,

literature and data analysis demonstrate that socio-demographic variables (e.g. low income level) are correlated with high and frequent use of the healthcare system. An examination of patient level data across equity variables will facilitate solutions.²⁶

In order to conduct such a system-wide analysis of the impact of the health equity indicators on health outcomes or system use, the TC LHIN could request aggregate data from all TC LHIN hospitals, as described above. The problem with this approach, however, is that it would create inaccurate, duplicate data because the data of a patient who visited three hospitals, for example, would be represented three times.

A better approach from a data quality perspective would be to collect all of the data in identifiable format to match and separate out duplicate data. Such a disclosure of identifiable personal health information for system planning would be best done through a prescribed planning entity. Under PHIPA, hospitals are permitted to disclose identifiable personal health information to prescribed planning entities, and prescribed planning entities are permitted to collect personal health information to:

analy[ze] or compil[e] statistical information with respect to the management of, evaluation or monitoring of, the allocation of resources to or planning for all or part of the health system, including the delivery of services²⁷.

²³ A rigorous evaluation of the method of de-identification is important to ensure that information cannot reasonably be re-identified. Some helpful resources for this evaluation include: Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, December 2010, online: <http://www.ethics.gc.ca/pdf/eng/tcps2/TCPS_2_FINAL_Web.pdf>, and the Toronto Academic Health Science Network Research Ethics Committee, *Principles for Development of Policy and Guidelines on Security of Personal Health Information Use for Research Purposes*, February 4, 2008, online: <http://www.research.utoronto.ca/wp-content/uploads/2009/03/TAHSN_PHI.pdf>.

²⁴ For a definition of “consistent purpose” see the *Freedom of Information and Protection and Privacy Act*, RSO 1990, chapter F.31, s 43.

²⁵ Toronto Central Local Health Integration Network “TC LHIN - Equity Data Collection Project Hospital Questions and Answers”, December 20, 2012.

²⁶ *Ibid.*

²⁷ *Supra* note 13, s 45(1).

Before the disclosure to a prescribed planning entity, it is recommended that hospitals ensure that:

(a) the entity has in place practices and procedures to protect the privacy of the individuals whose personal health information it receives and to maintain the confidentiality of the information; and

(b) the [Information and Privacy] Commissioner has approved the practices and procedures, if the custodian makes the disclosure on or after the first anniversary of the day this section comes into force.²⁸

Furthermore, it is advisable to review the prescribed planning entity's plain language description of its information practices so that hospitals are aware of the ways in which the entity collects, uses and discloses the identifiable information of hospitals patients²⁹. Lastly, it is also advisable, although not strictly necessary, for hospitals to enter into a contract with the prescribed planning entity to clarify:

- the information requested from the hospital,
- the technical format of the information,
- any qualifiers to the information that might impact its accuracy or completeness,
- the method and frequency of the information transmission, and
- any contingency plans that ought to be put into place, e.g. what would happen to the data if the entity changed its status, what would happen in the event of a privacy breach, etc.

While there are no current plans to disclose the Measuring Health Equity data, using a prescribed planning entity would be an ideal method both to protect the privacy of patients and to ensure that their data is accurately analyzed and compiled.

²⁸ *Ibid*, s 45(3).

²⁹ *Personal Health Information Protection Act, 2004*, OReg 329/04, s 18(2).

RESOURCES

Title	Date	File or Link
Anticipated Uses of Data for Health Care, Program Planning and Quality Improvement	March 11, 2013	http://torontohealthequity.ca/wp-content/uploads/2017/10/Anticipated-Uses-of-Data-for-Health-Care-Program-Planning-and-Quality-Improvement.pdf
Count Me In! Collecting Human Rights Based Data	November 26, 2009	http://www.ohrc.on.ca/en/count-me-collecting-human-rights-based-data-summary
Health Equity: Respecting Individuals and their Privacy	October 4, 2012 Prepared for Mount Sinai Hospital and TC LHIN: Measuring Health Equity Symposium	http://torontohealthequity.ca/wp-content/uploads/2017/10/Health-Equity-Respecting-Individuals-and-their-Privacy.pdf
Made in Sinai Health Equity Competencies: Delivering Healthcare to Diverse Communities	November 2008	http://www.mountsinai.on.ca/about_us/who-we-are/human-rights/CommunityConsultationM SH.pdf
Measuring Health Equity in TC LHIN Hospitals, News & Updates	January 22, 2013	http://torontohealthequity.ca/wp-content/uploads/2017/10/Measuring-Health-Equity-in-TC-LHIN-Hospitals-News-Updates.pdf
Participant Training Manual: A Guide to Demographic Data Collection for Admitting, Registration and Healthcare Staff in Toronto Hospitals	February 2013	http://torontohealthequity.ca/wp-content/uploads/2017/10/Participant-Training-Manual-A-Guide-to-Demographic-Data-Collection-for-Admitting-Registration-and-Healthcare-Staff-in-Toronto-Hospitals.pdf

Title	Date	File or Link
TAHSN Research Ethics Committee Principles for Development of Policy and Guidelines on Security of Personal Health Information Use for Research Purposes	February 4, 2008	http://www.research.utoronto.ca/wp-content/uploads/2009/03/TAHSN_PHI.pdf
Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans	December 2010	http://www.ethics.gc.ca/eng/policy-politique/initiatives/tcps2-eptc2/Default/
We Ask Because We Care, Answers to Frequently Asked Questions about Patient Demographic Data Collection Sample Pamphlet		http://torontohealthequity.ca/wp-content/uploads/2017/10/We-Ask-Because-We-Care-Answers-to-Frequently-Asked-Questions-about-Patient-Demographic-Data-Collection-Sample-Pamphlet.pdf

LEGISLATION

Canada Health Act, RSC 1985, c C-6.

Excellent Care for All Act, 2010, SO 2010, chapter 14.

Freedom of Information and Protection and Privacy Act, RSO 1990, chapter F.31.

Human Rights Code, RSO 1990, chapter H.19.

Personal Health Information Protection Act, SO 2004, chapter 3, schedule A.

Personal Health Information Protection Act, 2004, OReg 329/04.