STEP by STEP
Improving the health-care experience

Survey Review

A scan of existing and planned surveys of patient/client or caregiver experiences in transitions across care providers in Ontario

Fall 2010

Prepared by Brenda Tipper
For The Change Foundation

THE CHANGE FOUNDATION

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About The Change Foundation

The Change Foundation is an independent policy think tank, intent on changing the health-care debate, health-care practice and the health-care experience in Ontario.

A charitable foundation established in 1996 and funded though an endowment, The Change Foundation leads and leverages research, policy analysis, quality improvement and strategic engagement to enable a more integrated health-care system in Ontario designed with individuals and caregivers top of mind.

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1.INTRODUCTION

This review of patient/client or caregiver experience surveys in Ontario was initiated by The Change Foundation to support the implementation of its recently released Strategic Plan[1]. This plan focuses on improving the experiences of individuals as they move ***through*** Ontario's health-care system. As stated in the strategy document, the focus of the plan is:

> about probing, defining and identifying the value of rethinking and redesigning our health-care system from the user's point of view, mindful of the needs of the people for whom it was designed—those who need health services and the people who support them. It is about looking at the whole journey through the eyes of the individual, especially at transitions between services and at experiences over time. It is about capturing patient and caregiver experience and involvement with the health-care system, and using it as a tool to improve health outcomes and quality of life.

A key first step in the implementation is developing a more comprehensive understanding of the experience of health-care patients, clients and their caregivers with transitions across care sectors and services, and continuity of care. What problems (or good things) do they see? How do they experience these? What is the impact on their health? What is the impact on their day-to-day lives?

Over the past years, many health-care providers have begun to conduct regular surveys of the experiences of their patients and clients in order to support quality improvement. These surveys are also becoming an integral part of Canadian accreditation requirements. The recent passage of the *Excellent Care for All Act*[2] in Ontario has also established a legislative requirement for health-care providers to keep their finger on the experiences of their patients and clients.

There are also a number of population-based surveys that ask either general or targeted populations about their experiences with accessing and using health-care services. These surveys are often conducted by organizations with a mandate to collect and report health information, or by organizations examining questions of health policy.

However, while it is known that there are many providers and organizations conducting regular surveys of patient experience, what is not known is the extent to which these surveys can be used to develop the understanding of patient, client and caregiver experience as they move across providers and into and out of Ontario's health system.

This report describes the results of an environmental scan of what work is being done and what is planned in Ontario with respect to surveying patient/client and caregiver experiences in transitions as they move between health-care providers and across health-care sectors.

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1. The Change Foundation (2010). The Change Foundation 2010-2013 Strategic Plan. Hearing the stories, changing the story.

2. Legislative Assembly of Ontario (2010). An Act respecting the care provided by health-care organizations. Bill 46 (Chapter 14 Statues of Ontario, 2010).

2. KEY CONCLUSIONS

There are a number of existing surveys or research projects on patient/client or caregiver experience with the health-care system that include questions related to "transitions" or "continuity of care." In all of the surveys, questions related to continuity, transitions or navigation comprise a relatively small portion of the total questionnaire. They are not the key focus of the survey, but a part of a larger survey of experiences. As individuals respond to the questions, they may not have uppermost in their minds the issues of, or problems with, navigating across the health-care system.

None of the existing surveys or projects included in this review really examines directly, or in any comprehensive or systematic way, the experience of individuals and caregivers as they move in, out of, and across Ontario's health-care system over time and as their health changes. The need for a survey of experiences in this area is not just because it is interesting to know what is currently going on, but to obtain answers to the questions that can support system improvement. While existing surveys might provide some information regarding how individuals experience or feel about their transitions across the health-care system, it is unlikely that current projects can answer the questions that would be needed to design and support change to improve these experiences.

3.0 DESCRIPTION OF WORK AND METHODS

The review work consisted of two main steps. The first involved developing a list of patient/client or caregiver surveys and related projects that were relevant to The Change Foundation's work. In the second step, these surveys and projects were categorized into four main groupings in order to analyze patterns and provide commentary on how the content of the surveys relates to the experiences of patients/clients or their caregivers.

3.1 Approach to Developing List

The work of building the catalogue began with an initial list of surveys and projects related to the area of patient/client or caregiver experience developed from current Change Foundation partnerships. Additional projects or surveys were added through literature reviews and an Internet search of publications of results of patient/client or caregiver experience surveys of transitions across care providers. Initiatives of health-care providers (for example, hospitals and Community Care Access Centres) were also considered. Additional projects were identified through discussions with contacts regarding the surveys and projects on the list.

The surveys or projects included in the list reviewed had to satisfy the following criteria:

- The survey or project includes components related to patient/client or caregiver experiences with, and perspectives on, the health-care system; and
- The survey or project is based in Ontario, or is national in scope with a presence in Ontario.

There were some additional projects identified that did not meet the criteria above; for example, *The National Physician Survey* and work by the *Health System Performance Research Network* (HSPRN) researchers on understanding and identifying target populations for system improvement. Although these did not satisfy the criteria, they were included as potential projects and research that might provide useful information for developing work to examine patient/client or caregiver experience.

Table 1. Template used to catalogue patient/client or caregiver experience projects

Survey or Research Reference	
Sponsoring Organization(s) and Type	Organization(s) or partners for the survey work. Are they providers of care, funders, academic researchers, etc.?
Brief Description	Brief description of purpose or focus of survey work
Timing / Frequency	Is this a one-shot, ongoing, periodic type of survey? Work on the past only, or plans for the future?
Population Surveyed	Population-based, clients only, etc.
Sample Size and Methods	If a sample, how was it done, what is the sample size?
Overview of Content	Description of general survey content, tying back to purpose of the survey. Do the questions generally deal with one particular provider or health-care sector? Is there any content that addresses experience across different providers or sectors?
Relevance to The Change Foundation Work	Is there information coming out of the work that would be relevant to focus of The Change Foundation on continuity of care and transitions across providers? Could there be opportunities for partnering on future survey work, or learning from the surveys already conducted? Is there content or results from the survey that could help to inform Change Foundation work in this area?
Published Reports, Studies, Analyses	Any references to published reports or analyses of the survey results.
Organization Contact for Additional Information	
References	To questionnaires, results, documentation, etc.
Other Comments/Notes	

3.2 Development of Catalogue

A documentation template was completed for each of the surveys or projects that satisfied the criteria and for the additional projects as noted in Table 1 above. Appendix 1 includes the completed templates for each of the surveys or projects reviewed. Four main categories of surveys and projects were identified; each of the surveys or projects was grouped into one of these categories. The characteristics of each of the categories are listed below in Table 2.

Table 2. Description of categories of surveys and projects

Sponsoring Organization	Population Surveyed or Studied	Focus	Example	# Identified and Reviewed
Care providers	Patients/Clients or Caregivers	Experiences within the institution. Usually ongoing.	CCAC survey of client and caregiver experience	7
Health Information/ Policy Research Organizations	General population or identified sub-population	Population views or experiences with health-care system and services. Usually ongoing	Primary Care Access Survey (PCAS)	8
Directed Academic Research	Specific study targets	Varies. Usually one-time.	Continuity of Cancer Care	4
Others (projects related to theme but outside of scope)			National Physician Survey	5

4.0 ANALYSIS OF SURVEYS AND PROJECTS

The surveys and projects included in the review are listed in Table 3 together with the category into which they were grouped. The key findings of the analysis of the surveys and projects in each of the categories are discussed following the tables.

Table 3. List of surveys and projects included in analysis

Title/Reference		Key Organizations1	Category	Target	Status/Comments
1	CCAC Client and Caregiver Evaluation Survey	OACCAC	Care Provider	Survey of clients	Ongoing surveys
2	Hospital Patient Satisfaction Surveys	OHA	Care Provider	Survey of clients	Ongoing surveys
3	CAMH Survey of Client/ Patient Experience	CAMH	Care Provider	Survey of clients	Field work completed in June-July
4	Aging at Home Evaluation - Client and Caregiver Survey	AAH PMO	Care Provider	Survey of clients	RFP on hold
5	International Health Policy Survey of Adults	CWF with OHQC and HCC	Health Information/ Policy Research	Population survey	Most recent 2010 (to be published)
6	International Health Policy Survey of Sicker Adults	CWF with OHQC and HCC	Health Information/ Policy Research	Population survey	Most recent 2008 (published)
7	International Health Policy Survey of Primary Care Physicians	CWF with OHQC and HCC	Health Information/ Policy Research	Survey of providers of health care	Most recent 2009 (published)
8	Ambulatory Oncology Patient Satisfaction Survey (AOPSS)	CCO (Cancer Quality Council)	Care Provider	Survey of clients	Most recent reported results from 2009; considering new work on survey tool.
9	Primary Care Access Survey	MOHLTC	Health Information/ Policy Research	Population survey	Ongoing surveys
10	Canadian Community Health Survey	Statistics Canada	Health Information/ Policy Research	Population survey	Ongoing surveys
11	Canadian Survey of Experience with Primary Health Care	Statistics Canada with CIHI	Health Information/ Policy Research	Population survey	Most recent in 2008 (ongoing publications)
12	National Physician Survey	CFPC CMA RCPSC with CIHI	Other Project	Physician survey	Most 2010 (to be published), 2007 results available
13	QIIP Activity	QIIP	Other Project	Not applicable.	Work is progressing on initiatives related to patient engagement and mapping patient experience with primary health care.

Title/Reference		Key Organizations1	Category	Target	Status/Comments
14	Ontario Health Centres (CHCs)	AOHC	Care Provider	Survey of clients	Just beginning to initiate activity
15	Understanding and identifying target populations for system improvement	HSPRN	Other Project	Not applicable.	Administrative datasets have been used to identify utilization, costs and outcomes associated with patients with high needs.
16	An evaluation of continuity of cancer care through regional supportive care networks	SCCRU	Directed Academic Research	Intervention survey	Study completed and published
17	A Study of the Effectiveness of Specialist Oncology Nursing Case Management in Improving Continuity of Supportive Cancer Care in the Community (SONICS)	SCCRU	Directed Academic Research	Intervention survey	Study completed, publications forthcoming
18	Ontario long-term care residents and families survey	OHQC	Care Provider	Survey of clients	Survey tool being finalized - in pilot testing phase. Administration to begin in 2011
19	Uses of the Home Care Reporting System (HCRS) dataset	CIHI	Other Project	Not applicable.	Datasets for Ontario available.
20	Avoidable admissions initiative	OHQC OHA OACCAC LHINs MOHLTC	Other Project	Not applicable.	Work beginning
21	Health Care in Canada Survey	HCCS Partnership	Health Information/ Policy Research	Population survey	Last survey in 2007. No future work planned.
22	Report Card on Health Care	CMA	Health Information/ Policy Research	Population survey	Yearly since 2001. Most recent in 2010.
23	Measuring Integration of Cancer Services	CCO	Directed Academic Research	Providers of cancer care services	Research complete and published.
24	Evaluation of an intervention to improve the transition of patients between acute and community-based care	HSPRN, CHRU, SCCRU	Directed Academic Research	Intervention survey	Intervention to begin in October 2010; data collection proceeding through to March 2011.

Note: See Appendix 3 for list of organizational acronyms

4.1 Surveys sponsored by health-care providers

The patient/client or caregiver experiences in this category generally have a main objective of understanding the experiences of the patients/clients (and their caregivers) who received health services from the provider organization in order to support quality improvement within the organization. The health-care providers conducting these surveys included hospital facilities (acute, continuing complex care, rehabilitation, paediatric), Community Care Access Centres (CCACs) in Ontario, Cancer Care Ontario (CCO), and the Centre for Addiction and Mental Health (CAMH). Additionally, Community Health Centres in Ontario and some Family Health Teams are in the initial stages of developing and implementing survey tools to focus on the experiences of their patient/clients or caregivers, and the Ontario Health Quality Council (OHQC) is beginning work to support and coordinate surveys of residents of long-term care facilities.

These surveys in this grouping have evolved over the past ten years from initial attempts by individual organizations to understand the experiences of their patients/clients in their focus on quality improvement. The work of the Hospital Report Research Collaborative in reporting patient satisfaction as one of the four quadrants of the balanced scorecard supported more systematic and standardized participation of hospitals in this survey work. Also, as new standards have been developed or revised by Accreditation Canada, surveys of the experiences of patients/clients have become an accreditation requirement. The OHQC has recently begun leading work to support the implementation of patient/client or caregiver experience surveys in long-term care facilities in Ontario. Finally, Ontario's *Excellent Care for All Act* has made satisfaction surveys of patients/clients a legislated requirement for hospitals and it is anticipated that this will eventually include most other providers of health-care services. The Ontario Ministry of Health and Long-Term Care (MOHLTC), together with provincial provider organizations and the OHQC are presently addressing how these survey requirements might be implemented.

In the case of surveys by hospitals and CCACs, the survey work is coordinated through provincial organizations—the Ontario Hospital Association (OHA) and the Ontario Association of Community Care Access Centres (OACCAC) respectively. These organizations have negotiated blanket contracts with the research companies doing the field work (NRC+Picker and Ipsos Reid). However, individual hospitals and CCACs make their own arrangements with these companies with respect to sample sizes and timing of survey work.

Sampling methodologies for the CCAC and hospital surveys involve the providers submitting patient/client lists periodically to the companies conducting the field work with some specific exclusions possibly noted. The field work company selects a random sample from the lists that is large enough to generate the desired number of responses based on expected response rates and the surveys are conducted through phone or mail. In the case of CAMH, survey coordinators distributed printed questionnaires to patients/clients receiving outpatient or inpatient services (with the exception of the emergency department) who were willing to complete the survey during the period of survey administration.

Many of the surveys that are currently in place are ongoing and regular. The CCAC surveys of client and caregiver experience are conducted in quarterly waves. Thirteen of the 14 CCACs in Ontario now participate. The hospital surveys are also generally ongoing. CAMH recently conducted its first survey of patient/client experience (field work in June and July, 2010) and is presently analyzing the results. However, they do not expect to repeat the survey until 2012 at the earliest. CCO, through the Cancer Quality Council of Ontario, has been conducting an annual survey of experiences of patients/clients receiving ambulatory oncology services since 2004. High level results of these surveys have been reported in the annual Cancer System Quality Index (CQSI)[3].

A number of primary care provider organizations are in the initial phases of planning and developing survey tools to obtain information about the experiences of their patients/clients and caregivers. These include Family Health Teams through the Quality Improvement and Innovation Partnership (QIIP) initiatives and Community Health Centres in Ontario. To date there are no reports of validated survey tools that have been administered in a systematic way within this sector.

Commentary

The content of the surveys is specific to the experiences of patients/clients or caregivers with the provider organization, or, in the case of CCACs, across CCAC-funded service providers. Often, much of the content is devoted to how patients /clients or caregivers perceived or experienced interactions with the provider organization's staff (clinicians and others); for example, did individuals feel they were treated with respect, did staff provide conflicting information or instructions, etc. (examples of survey questions are listed in Appendix 2).

Some surveys have questions that deal with the admission/intake and discharge processes. These might be

3. Results for 2010 can be found at the cqsi website: http://csqi.cancercare.on.ca/cms/one.aspx?portalid=63405&pageid=63412

useful in assessing some aspects of patient/client or caregiver experiences with getting access to or getting into the provider's services. Questions around the discharge process are often labelled or grouped into a domain of experience called *continuity of care* or *transitions*. The questions in these areas tend, however, to deal with whether patients/clients or caregivers felt they were ready for discharge and if they received sufficient information, for example, did individuals feel that they knew who to contact in the event of problems, did they feel they had sufficient information to understand potential side effects of medications, etc. For the most part, they do not address coordinating follow-up or continuing care for the patient/client's health issues with other health-care service providers.

4.2 Population-based surveys sponsored by health information or research organizations

The surveys included in this category were population-based, often with an objective of providing a broad perspective on public or patient/client perceptions of access to, utilization of, and experiences with, health-care services and the health-care system. These surveys are coordinated or supported by various health information or health policy research organizations, including for example, Statistics Canada, the Canadian Institute for Health Information (CIHI), the MOHLTC, and The Commonwealth Fund.

The organizations that conduct or sponsor these surveys are varied, and some of them have collaborated with each other on different surveys. The Commonwealth Fund is a private foundation that undertakes health policy research. Since 1998, this foundation has sponsored an annual *International Health Policy Survey*[4]. Canada has been one of the countries included in these surveys. The survey focus, along with the target population, changes somewhat each year, but over the last few years the emphasis has been on primary care systems. Although the publications from The Commonwealth Fund have focused on how the U.S. health system compares to that of other countries, Canadian organizations—the Health Council of Canada, the OHQC and the Commissaire à la Santé du Quebec—have partnered with The Commonwealth Fund to sponsor a larger sample size in Canada, Ontario and Quebec, and have published their own analyses of results. Statistics Canada conducts the Canadian Community Health

Survey (CCHS), which reports information about utilization of and access to health services together with information about health status. CIHI and the Health Council of Canada have also partnered with Statistics Canada to develop and administer a survey focusing on the experience of Canadians with primary health care. Finally, since 2006, the MOHLTC has conducted a general population survey in Ontario to obtain information focused on access to and utilization of primary care services.

The surveys in this category have all been administered via telephone using computer assisted interviewing processes. Statistics Canada uses an elaborate sampling method to ensure coverage for all health regions in all provinces and territories and targets a sample size sufficient to report results at the provincial or health region levels. The Commonwealth Fund surveys and Primary Care Access Survey (PCAS) both use random digit dialling sampling methods. Sample sizes for PCAS are designed to support reporting of results for Ontario on a quarterly basis and for Local Health Integration Networks (LHINs) on an annual basis. Commonwealth Fund survey sample sizes are generally smaller and are designed to support reporting of national results; however as noted above, the OHQC and Health Council of Canada have sponsored increased national and Ontario samples in order to support more detailed analysis for Canada and Ontario.

Some of these surveys have been administered on a fairly regular basis over the past ten years, although usually less frequently than an annual cycle. An exception is the PCAS, which has been ongoing in the field and administered in quarterly waves since January 2006. While the Commonwealth Fund conducts an *International Health Policy Survey* every year, the focus of the survey has changed somewhat each year. The last three surveys with published results have examined: adults' perspectives on and experiences with health-care systems (2007); perspectives on and experiences with health care for sicker adults (2008); and, survey of primary care physicians (2009). While results will not be reported until late in 2010, field work for the survey has been completed and is again focused on the general perspectives and experiences of adults in the participating countries. Statistics Canada conducts the CCHS yearly, although some of the content varies from year to year. The Canadian Survey of Experiences with Primary Health Care (CSE-PHC), conducted by Statistics Canada and sponsored by CIHI and the Health Council of Canada has been conducted twice—an initial version in 2007 and a reworked version focusing on CIHI primary health-care indicators in 2008. Although the survey is technically "active", there are no current plans to repeat it in the near future.

4 A list of these yearly surveys can be found at: http://www.commonwealthfund.org/Surveys/View-All.aspx?topic=International+Health+Policy

Commentary

The data collected through these surveys have some potential to provide information relevant to the experiences of individuals in accessing and utilizing a range of health services, or health services in general. For example, the 2008 Commonwealth Fund survey included topics such as: perceptions of inefficient or wasteful care, relationship to a regular care provider, problems with coordination or duplication of medical tests, coordination of specialist care (focusing on availability of information), hospital discharge planning and transitional care (again focused on availability of information), medication management reviews, and patient engagement in care for chronic conditions. Most of these topics were also included in the CSE-PHC survey. Although PCAS is focused primarily on access to and utilization of primary care services, it includes questions about a broad range of utilization (yes or no) of other health-care services, including services from a range of allied health professionals and complementary/alternative medicine providers. CCHS and CSE-PHC include questions about types of barriers in access to health-care services; these could be used to develop some information about the extent to which barriers result from poor coordination or the inability of individuals to connect with the service providers they feel they need.

The population surveys included in this group often include questions that could be used to develop richer socio-demographic and health status profiles of individuals that are frequent users of a variety of health services, or that report access barriers. These profiles could prove useful in assessing or determining target groups in order to develop a more detailed understanding of the issues facing these sub-groups.

4.3 Surveys associated with research initiatives

A small number of the projects reviewed consisted of smaller, targeted surveys used to answer specific research questions. They share few common characteristics. These projects are briefly summarized below.

Continuity of cancer care. There were two research projects related to understanding continuity of cancer care that surveyed control and study groups, pre- and post-intervention, to determine if experiences with continuity had improved. Results from one of these studies have been published, while a paper with the results of the second is in preparation.

Evidence-informed strategies for improving quality and safety in care transitions. This is a Health System Performance Research Network (HSPRN) research project that is just getting underway. The objective is to deliver an intervention to improve the transition from acute hospitals to community care. The evaluation of the intervention will include structured interviews with individuals (target is approximately 150) regarding their experience with care coordination in the community.

Aging at Home Program Evaluation. This project is an evaluation of the MOHLTC's Aging at Home strategy and investments, and is being run through an evaluation project management office associated with the Institute of Clinical and Evaluative Sciences (ICES). A Request for Proposals for an evaluation survey of clients (or their caregivers) of community support services was issued early in 2010. This survey would have examined the experiences of clients receiving community-based services as part of the Aging at Home program. However, the evaluation steering committee, together with the MOHLTC, are reviewing their strategy for evaluation and the RFP has since been put on hold. No decision has yet been made as to whether survey work associated with the evaluation will proceed.

Commentary

The specific research studies can provide an opportunity to reference more in-depth or detailed information about the experiences of patient/clients or caregivers with transitions across care providers. While some of these might be focused on a particular area of health care (i.e., cancer care), the scope can still include experiences with a broader group of care providers than might be possible with provider-based surveys, while at the same time delving in a more detailed way into questions of patient/client experience across sectors. However, the surveys associated with the projects listed above are directed to individuals receiving an intervention (and a control group) and could not likely be generalized to a broader population group.

4.4 Other surveys and projects

The projects in this category did not meet the criteria for review described earlier; in particular, they do not address patient/client or caregiver experiences. However, they may potentially be relevant through providing information about transitions, continuity or utilization of services within the health-care system, and are included here for information.

4.4.1 Surveys of health-care providers

Some research initiatives have surveyed providers of health care for their perspectives on questions associated with information sharing or connections among providers caring for the same patient. The projects that fell into this category are described briefly below. These should be considered illustrations of the types of activity in these areas. They are by no means a comprehensive picture.

Development of a measure of cancer system integration. Dobrow et al (2009)[5]developed a survey of providers of cancer care to be used to measure cancer system integration.

National Physician Survey. The National Physician Survey has been conducted in 2004, 2007 and 2010 (2004 and 2007 results have been published and are available). It is sponsored jointly by the College of Family Physicians of Canada, the Canadian Medical Association and the Royal College of Physicians and Surgeons of Canada. In 2010, CIHI also participated in sponsoring the survey. The 2010 survey contains questions related to the ease of working with other clinicians (including allied health providers) to care for patients, provider perceptions of the accessibility of other clinicians to their own patients, and use of electronic systems to share information.

4.4.2 Use of administrative data

Administrative datasets provide information about utilization of health-care services across a number of different sectors (although not always comprehensively), including, for example, acute hospital inpatient care, emergency departments, outpatient procedures, home care, physician visits and prescription medications. These datasets, particularly if linked, can generate profiles of utilization across sectors and could be useful in identifying target populations of individuals who are "heavy users" of a range of health-care services. These datasets can also provide information on outcomes for both patients/clients and caregivers. The following are examples of relevant applications of administrative data.

Understanding and identifying target populations for system improvement. This research program is being run by researchers in the HSPRN. It aims to use administrative data to identify target populations with complex conditions requiring care from a range of providers, and identify patterns of utilization, outcomes and costs among the individuals in these groups.

Supporting Informal Caregivers. The Heart of Home Care. This report[6] is an example of how administrative datasets could support looking at outcomes. It was produced by CIHI using the interRAI Resident Assessment Instrument—Home Care (RAI-HC©) included in the Home Care Reporting System. The report included an analysis of rates of caregiver distress and noted elevated risks among those caring for individuals with no home health care or nursing care services.

Commentary

As noted above, the projects that fell into this category do not survey patients/clients or caregivers about their experiences or perspectives. However, they could lay some groundwork for understanding target populations, analysing outcomes, and for flagging issues that might have been raised by providers of health care in this area.

5 Dobrow MJ, et al (2009). "Measuring Integration of Cancer Services to Support Performance Improvement: The CSI Survey". Healthcare Policy. 5(1):35-53.

6 CIHI (2010). Supporting Informal Caregivers. The Heart of Home Care. The Canadian Institute for Health Information. Ottawa: 2010.

5.0 CONCLUDING NOTES

As stated at the outset, there are a number of existing surveys or research projects on patient/client or caregiver experience with the health-care system that include questions related to "transitions" or "continuity of care." In all of the surveys, questions related to continuity, transitions or navigation comprise a relatively small portion of the total questionnaire. They are not the key focus of the survey, but a part of a larger survey of experiences. As individuals respond to the questions, issues of, or problems with, navigating across the health-care system may not be uppermost in their mind.

Provider-focused surveys by their nature cannot look across to other providers or sectors. Given the sampling methodologies and protocols, providers would not in most cases, be able to identify which of their patients received care from other providers for a related condition, the nature of the related care, and when it might have happened.

Where surveys include a dimension or domain addressing "continuity of care" or "transitions" it has often been defined in a purely informational way. For example, questions may include whether individuals knew who to contact following discharge, whether they understood what side effects to watch for, whether they felt that providers had the results of the most recent diagnostic tests, etc. Haggerty et al (2003)[7]suggest that "informational continuity" is only one of three important aspects of overall overall continuity; two other important aspects are "relational continuity" and "management continuity." In the same paper they also conclude that "[c]ontinuity is not an attribute of providers or organisations … [it] is how individual patients experience integration of services and coordination."

None of the existing surveys or projects included in this review really examines directly or in any comprehensive or systematic way *the experience of individuals and caregivers as they move in, out of, and across Ontario's health-care system over time and as their health changes*. The need for a survey of experiences in this area is not just because it is interesting to know what is currently going on, but to obtain answers to the questions that can support system improvement. While existing surveys might provide some information regarding how individuals experience or feel about their transitions across the health-care system, it is unlikely that current projects can answer the questions that would be needed to design and support change to improve these experiences.

7 Haggerty JL et al.(2003). "Continuity of Care: A Multidisciplinary Review." British Medical Journal 327(7425): 1219–21.

APPENDICES

1. Survey Inventory Catalogue
2. Examples of Survey Content (Questions)
3. List of Organizational Acronyms

APPENDIX 1. Survey Inventory Catalogue

Survey or Research Reference	1. CCAC Client and Caregiver Evaluation Survey (CCEE)
Sponsoring Organization(s) and Type	Coordinated and managed by the Ontario Association of Community Care Access Centres (OACCAC) for the 14 Community Care Access Centres (CCAC) in Ontario. Survey work has been planned and managed by a Task Group, reporting through to the CCAC CEO Council. Care provider survey of patients/clients or caregivers.
Brief Description	Survey of the experience of CCAC clients and their caregivers. The OACCAC manages the procurement contract with Ipsos Reid and houses a common database of raw data survey results. Each CCAC contracts separately with Ipsos Reid to administer the core survey for a minimum of 1,000 clients/caregivers annually.
Timing / Frequency	The survey is intended to be an ongoing evaluation tool, with four sample waves conducted annually in each CCAC. To date (as of August 2010) seven CCACs have conducted a full year of four annual waves, four have done two waves, and two have completed one wave. One CCAC has yet to begin surveys.
Population Surveyed	The survey population comprises clients and caregivers of the specific CCACs—i.e., individuals who have received CCAC services. Both active and discharged clients are included in the survey population.
Sample Size and Methods	A minimum of 1,000 respondents are to be surveyed in each CCAC over the period of a year. Some CCACs have chosen to conduct over 1,500 surveys per year. For each CCAC, samples are based on a random selection of clients from either proportionate or disproportionate strata, depending on plans developed with the CCAC. Strata may include: service level, geographic region, service type and/or provider (e.g., nursing, homemaking care, physiotherapy, etc.)
Overview of Content	The core survey covers the following broad areas: overall experiences (i.e., covering all services received); first contact/intake process; case management/care coordination (over CCAC services); service provision (for each service type); discharge and transitions (including long-term care referrals where appropriate); final thoughts and demographic profile. There is a question in the section on discharge and transitions that ask respondents about whether they felt they were provided with sufficient information about how to get additional services they require. The questions on long-term care referrals also ask the respondents if they felt they received sufficient information about options for long-term care.
Relevance to The Change Foundation Work	It could be useful to examine responses around the first contact/intake process and the discharge and transitions process to see what types of concerns might be identified, but this would more likely be a starting point for informing development of a different survey tool or determining a target population. To be more appropriate there would need to be additional content dealing with experiences with other care providers and transitions to/from CCAC care. E.G. looking at CCAC referral source (acute care hospital, family physician, etc.) There could be opportunities in questions in the first contact/intake section or the discharge and transitions section to talk about referrals from other sectors, how individuals were "connected" to CCAC, whether CCAC seemed to have some information about or understanding of their situation, etc. Similarly post-discharge questions could attempt to examine services that clients used outside of the CCAC umbrella. The questions regarding Case Management could provide some indication of whether the Case Manager was able to connect the individual with needed services and coordinated CCAC services overall.
Published Reports, Studies, Analyses	Standard reports are to be generated from survey data, but are not yet available. The scope of public reporting of results has not yet been determined, but will likely be developed in the next year.
Organization Contact for Additional Information	Anne Bell, Director of Procurement Services, OACCAC

References	1. Measurement Tool Certification Application to Accreditation Canada. Provides background on development of the tool. Describes roles of OACCAC, CCACs, CCEE Task Group, Ipsos Reid. Describes sampling methods, privacy protections, etc. 2. CCEE questionnaire 2009-07. Indicates questions that were added at the request of the OHQC 3. CCEE questionnaire final. Final version of the core questions for the survey. 4. CCEE logic model. Indicates intermediate and long-term client outcomes that were used to focus the development of the survey. 5. CCEE report to CEO Council 2010-02. Report by the Task Force on the current status of the progress to date and work plan for 2010. 6. Email from A. Bell.
Other Comments/Notes	The report to the CEO Council indicates that analyses of initial results show caution is required when comparing results across CCACs. The 14 CCACs have client bases with different characteristics, some of which are highly related to satisfaction scores.

Survey or Research Reference	2. Hospital Patient Satisfaction Surveys (NRC+Picker)
Sponsoring Organization(s) and Type	The OHA contracts with NRC Picker Canada on behalf of the hospitals for administration of common (with provisions for optional content) patient/client experience surveys. OHA coordinates a standardized process and negotiates a "best price" with NRC+Picker. Care provider survey of patients/clients or caregivers.
Brief Description	Standard survey tool of patient experience in hospitals. Individual hospitals may add up to 5 questions of optional content. A number of surveys specific to services have been developed. These are ambulatory care, day surgery, emergency department, acute inpatient, oncology, maternity, paediatric, mental health, complex continuing care and rehabilitation. 113 of 154 public hospitals (including all teaching and large community hospitals) in Ontario are currently participating to some degree. The current estimated cost of the survey over all participating hospitals is $3 million annually.
Timing/Frequency	NRC+Picker administers the survey on behalf of participating hospitals. Survey timing and schedules are determined by individual institutions. Inpatients (including maternity and paediatrics) and ED patients are continuously surveyed. For the most part, patients in the other sectors are surveyed at specific points in time.
Population Surveyed	The population surveyed consists of client/patients that have been served by (or remain residents of) the institutions/services listed above.
Sample Size and Methods	For inpatient and emergency department surveys, individual hospitals were required to have a minimum sample of 100 patients annually in order to participate in the Hospital Report series. For other sectors the number was set somewhat lower due to the smaller patient populations. Depending on individual hospital needs, they may contract with NRC+Picker for a substantially larger sample. For IP and ED, hospitals needed 100. For other sectors, the number was lower because of the smaller patient populations. Different survey methods are used for certain populations and specialty facilities (e.g., direct interviews with residents of CCC facilities).
Overview of Content	Although surveys are specific to the type of institution or service, content is focused on the experiences of patients/clients within the institutions. Questions are commonly related to communication and interactions with facility staff (physicians, nurses and other), admitting processes, coordination of care services and information within the facility, physical comfort, etc.
Relevance to The Change Foundation Work	Domains on "continuity and transitions" includes questions related to whether patients felt they had sufficient information on discharge to meet their care needs (had sufficient information to manage their own care, knew when to contact doctor, knew if follow-up appointments were required, understood medications, etc.). The survey for rehabilitation includes a question of whether referrals for home care were made if needed. The OHA and OACCAC have set up a steering committee to coordinate common issues, such as transitions between hospital and home care. The steering committee will be working with initiatives around reducing avoidable admissions.

Published Reports, Studies, Analyses	Hospital Reports series (available at http://www.hospitalreport.ca or http://www.hsprn.ca/reports/bysector.html)
Organization Contact for Additional Information	Lou Reidel, Director, Health Finance and Research, OHA Sarena Weil, Consultant, Hospital Report and Patient Satisfaction, OHA
References	1. Hospital Reports documentation. These reports include descriptions of survey methods, domains and related survey questions. • IP technical report • ED technical report • Mental health technical report (all quadrants, not just patient satisfaction) • Rehabilitation technical report • CCC resident/family technical report 2. Current survey questionnaires for: inpatient, rehabilitation, CCC (resident), CCC (family) 3. OHA slide deck. 4. Phone call with L. Reidel and S. Weil.
Other Comments/Notes	The survey results have been used in the past and may be used again in the future to support public reporting. Up until 2008, the Hospital Report Research Collaborative and CIHI analyzed the raw survey data and developed indicators for public reporting in the Hospital Reports series. Results from the Emergency Department patient surveys were to be publicly reported for hospitals participating in the "ER Pay for Results" beginning in 2010. However, this has been postponed by the surveying and reporting requirements included in the *Excellent Care for All* Act. The OHA is presently working with hospitals and the MOHLTC to develop standards for these requirements. Further information on survey and reporting plans is likely to be available later in the fall. NRC+Picker has also been working with the OHA to develop indicators from the surveys that could be used for public reporting on http://www.myhospitalcare.ca/Pages/homepage.aspx. Relative to other patient experience survey tools, the NRC+Picker tool is felt to best support quality improvement work in institutions.

Survey or Research Reference	3. Centre for Addiction and Mental Health (CAMH) survey of client/ patient experience
Sponsoring Organization(s) and Type	CAMH for services provided to patients/clients Care provider survey of patients/clients or caregivers.
Brief Description	Survey is intended to evaluate the experiences of CAMH inpatients and outpatients, primarily focused on quality improvement and requirements for accreditation and was developed with the partnership of Accreditation Canada.
Timing/Frequency	The survey was administered over June 15 to July 31. In principle, the survey would be conducted again with the accreditation cycle, but this is likely 2-3 years out.
Population Surveyed	Population consists of clients who were present as inpatients or receiving outpatient services at CAMH during the survey field work period (June 15–July 31). Clients of the ER were excluded from the survey as there was no appropriate survey tool for this group.
Sample Size and Methods	Surveys were given to clients by trained client surveyors who visited all clinical areas (except the ER) and gave out and then collected the completed questionnaires. A total of approximately 900 surveys were completed/returned over the survey period.
Overview of Content	The questionnaire was developed from a number of sources, including the NHS acute mental health acute inpatient services client survey, the NRC+Picker mental health services tool, the ECHO survey tool for managed behavioral health-care organizations (from the CAHPS family of surveys), and the 2009 Client Perception of Care Survey from Mental Health Centre Penetanguishene. The content used by CAMH included dimensions covering: • pathways in and out of care (referral process, wait times, admission, ER, and timing and support at discharge) • environment and services • interactions with staff (including continuity of care across staff members) • client centred care • meaningful activities • outcomes and overall experiences
Relevance to The Change Foundation Work	The NHS questionnaire includes questions on discharge related to whether the client was contacted by the hospital for post-discharge follow-up, whether they were given emergency contact and other follow-up information, and whether there were delays in discharge (including waiting for availability of community workers). The ECHO survey tool includes questions about the coordination of, access to, waiting times, etc. of services by the company or organization responsible for the counseling benefits.
Published Reports, Studies, Analyses	Survey results are still being analyzed. It is anticipated that use will likely be internal, but possible that some research or academic papers may be published in the future (J. Durbin would be the primary researcher involved).
Organization Contact for Additional Information	Monica Haberman, Centre for Addiction and Mental Health.
References	1. Experiences with Care and Health Outcomes (ECHO) Survey for Adult Managed Behavior Healthcare Organizations 2. Client Perception of Care 2009 Survey, Mental Health Centre Penetanguishene 3. NRC+Picker, Satisfaction with Outpatient Mental Health Care survey questionnaire 4. National Health Service, Mental Health Acute Inpatient Service Users Survey Questionnaire 5. CAMH, Client Experience Survey, Purpose of Survey and Proposed Survey Dimensions 6. Phone call with M. Haberman.

Survey or Research Reference	4. Aging at Home Evaluation—Client and Caregiver Experience Survey
Sponsoring Organization(s) and Type	Aging at Home Evaluation Project Management Office Care provider
Brief Description	A survey of the experiences of clients and caregivers who are receiving community support services (excluding those receiving home-care services). This survey is intended to be complementary to the CCAC client and caregiver experience surveys. Note: The RFP that was issued for this survey by the AAH Evaluation was put on hold pending a review of priorities with new Ministry directives. There are no immediate plans to reissue the RFP.
Timing/Frequency	One-time survey to evaluate the implementation and outcomes of the Aging at Home program
Population Surveyed	Clients receiving Community Support Services (excluding those receiving home-care services)
Sample Size and Methods	Sample sufficient to analyze and report results at the LHIN level (roughly 3,000 in total).
Overview of Content	Questionnaire content is similar to that for the CCAC client and caregiver experience survey, focusing on experiences with the services received from a Community Service provider. The questionnaire that was part of the RFP included regarding *unmet community service* needs as well as whether services were arranged in a convenient way and whether the providers seemed informed and up-to-date with information about the client.
Relevance to The Change Foundation Work	Although this survey was to focus on clients of community service providers, some of the questions could prove useful for identifying barriers to coordination of services and whether individuals felt they were receiving the services that they needed.
Published Reports, Studies, Analyses	Not applicable.
Organization Contact for Additional Information	Jacqueline Stevenson, Aging at Home Evaluation Project Management Office
References	1. Aging at Home Client and Caregiver Experience RFP (includes proposed questionnaire) 2. Aging at Home Strategy Evaluation Framework 3. Aging at Home Evaluation Project Management Office 4. Email from L. Corbett, Aging at Home Evaluation Project Management Office

Survey or Research Reference	5. International Health Policy Survey of Adults
Sponsoring Organization(s) and Type	The Commonwealth Fund Health Information/Policy Research Organization
Brief Description	The Commonwealth Fund has conducted an annual international health policy survey since 1998, with Canada included among the countries surveyed. In 2007, the survey focused on adults' experience with the health-care system. Other countries included in the 2007 survey were: Australia, Germany, Netherlands, New Zealand, the U.K., and the U.S. A similar survey has been repeated in 2010; the 2010 survey has expanded to include additional countries.
Timing/Frequency	The field work for the annual international health policy surveys is conducted through the spring months. Results are released and published in the fall. Organizations that have partnered with the Commonwealth Fund on the particular survey may release their own analyses of the data following the release of the Commonwealth Fund publications. For the past six years, the Commonwealth Fund International Health Policy Survey has worked through a cycle of three surveys—the survey of adults (2004, 2007, 2010), a survey of sicker adults (2005, 2008) and a survey of primary care physicians (2006, 2009).
Population Surveyed	This is a population-based survey of adults in each of the countries.
Sample Size and Methods	The 2007 and 2010 surveys were conducted in Canada by Harris Interactive. This was a telephone-based survey. The sample size in Canada for the 2007 survey was approximately 3,000.
Overview of Content	This was a fairly comprehensive survey covering adults' experiences with and perceptions of health-care services. Content covered: overall views on the health system; access to care and care coordination; experience with primary care physicians and use of teams/ non-physician specialists; use of specialists and coordination between family physicians and specialists; hospitalization and ER use; prescription medication use; experience with medical errors; and access to medical records. Social and demographic information such as level of education, marital status, income level, immigration status, racial/ethnic group is also captured
Relevance to The Change Foundation Work	The survey includes a number of content questions related to experience with coordinating and accessing care across providers. These include perceptions of waiting times, flow of information, duplication of tests, etc. Analysis of results for some of these questions may provide indications of areas of focus, and help to identify further research questions for follow-up. However, the Ontario sample from the 2007 survey is likely not large enough to support stratified analyses of results on these questions.
Published Reports, Studies, Analyses	Numerous publications have been generated from the collected data, by the Commonwealth Fund and by partner organizations. Links to the Commonwealth Fund publications can be found at: http://www.commonwealthfund.org/Content/Surveys/2007/2007-International-Health-Policy-Survey-in-Seven-Countries.aspx
Organization Contact for Additional Information	Ontario/Canadian partners: Heather Dawson and John Abbott, Health Council of Canada Imtiaz Daniel, Ontario Health Quality Council
References	1. 2007 International Health Policy Survey Questionnaire. 2. 2007 International Health Policy Survey Topline Results. 3. Phone call with H. Dawson, Health Council of Canada. 4. Meeting with I. Daniel, Ontario Health Quality Council.

Survey or Research Reference	6. International Health Policy Survey of Sicker Adults
Sponsoring Organization(s) and Type	The Commonwealth Fund Partners on the 2008 survey of sicker adults included The Health Council of Canada, the Ontario Health Quality Council, and Commissaire à la Santé du Quebec Health Information/Policy Research Organization
Brief Description	The Commonwealth Fund has conducted an annual international health policy survey since 1998, with Canada included among the countries surveyed. In 2008, the survey focused on the experience of "sicker" adults' (defined as: health is fair or poor OR serious illness in past 2 years OR hospitalized OR had major surgery in past 2 years OR having a chronic condition) experience with the health-care system. Other countries included in the 2008 survey were: Australia, France, Germany, the Netherlands, New Zealand, the U.K, and the U.S. A similar survey is planned for 2011.
Timing/Frequency	The field work for the annual international health policy surveys is conducted through the spring months. Results are released and published in the fall. Organizations that have partnered with the Commonwealth Fund on the particular survey may release their own analyses of the data following the release of the Commonwealth Fund publications. For the past six years, the Commonwealth Fund International Health Policy Survey has worked through a cycle of three surveys—a survey of adults (2004, 2007, 2010), a survey of sicker adults (2005, 2008, 2011 planned) and a survey of primary care physicians (2006, 2009).
Population Surveyed	Population-based survey of sicker adults—defined as individuals whose health is fair or poor, or have had a serious illness in the past 2 years, or have been hospitalized or had major surgery in the past 2 years, or have a chronic condition.
Sample Size and Methods	The 2008 survey was conducted in Canada by Harris Interactive. This was a telephone-based survey. The sample size in Canada for the 2008 survey was approximately 2,650.
Overview of Content	Fairly comprehensive survey covering adults' experiences and perceptions in areas such as: perceptions of organization of medical care, sharing of information, coordination of care, arranging access to other care providers appointments, follow-up, sharing and having appropriate information available, experience with hospital care and coordination following hospitalization, readmissions and ER use following discharge. Social and demographic information such as level of education, marital status, income level, immigration status, racial/ethnic group is also captured.
Relevance to The Change Foundation Work	The surveys of adults' experience with health care include a number of content questions related to experience with coordinating and accessing care across providers and include perceptions of waiting times, flow of information, duplication of tests, etc. Analysis of results for some of the key questions may provide indications of areas of focus, and help to identify further research questions for follow-up. However, it's unlikely that the Ontario sample is sufficient for detailed stratified analysis of results on these questions.
Published Reports, Studies, Analyses	Numerous publications have been generated from the collected data, by the Commonwealth Fund and by partner organizations. Commonwealth Fund publications can be found through the links to yearly surveys at: http://www.commonwealthfund.org/Surveys/View-All.aspx?topic=International+Health+Policy The Health Council of Canada has published 2 reports using the results of the 2008 survey, available at: http://healthcouncilcanada.ca/en/index.php?option=com_content&task=view&id=237&Itemid=29 The Ontario Health Quality Council included results from the 2008 survey of sicker adults and 2009 survey of primary care physicians in the 2010 annual report, available at: http://www.ohqc.ca/pdfs/2010_report_-_english.pdf
Organization Contact for Additional Information	Ontario/Canadian partners: Heather Dawson and John Abbott , Health Council of Canada Imtiaz Daniel, Ontario Health Quality Council
References	1. The 2008 Commonwealth Fund International Health Policy Survey of Sicker Adults. Topline Results (includes survey questions). 2. Phone call with H. Dawson, Health Council of Canada 3. Meeting with I. Daniel, Ontario Health Quality Council.

Survey or Research Reference	7. International Health Policy Survey of Primary care physicians
Sponsoring Organization(s) and Type	The Commonwealth Fund. Partners on the 2008 survey of sicker adults included The Health Council of Canada, the Ontario Health Quality Council, and Commissaire à la Santé du Quebec Health Information/Policy Research Organization
Brief Description	The Commonwealth Fund has conducted an annual international health policy survey since 1998, with Canada included among the countries surveyed. In 2009, the survey focused on the practices and experiences of primary care physicians. Other countries included in the 2009 survey were: Australia, France, Germany, Italy, the Netherlands, New Zealand, Norway, Sweden, the U.K., and the U.S.
Timing/Frequency	The field work for the annual international health policy surveys is conducted through the spring months. Results are released and published in the fall. Organizations that have partnered with the Commonwealth Fund on the particular survey may release their own analyses of the data following the release of the Commonwealth Fund publications. For the past six years, the Commonwealth Fund International Health Policy Survey has worked through a cycle of three surveys—a survey of adults (2004, 2007, 2010), a survey of sicker adults (2005, 2008, 2011 planned) and a survey of primary care physicians (2006, 2009).
Population Surveyed	Primary care physicians, defined as family physicians and general practitioners.
Sample Size and Methods	A random sample of primary care physicians were mailed surveys to complete. The sample was taken from public and private lists of family physicians and general practitioners. The sample size in Canada was approximately 1,400 responses; however, the response rate was only 35%.
Overview of Content	The survey included questions regarding difficulties in coordinating care for patients; use of information systems to share information (e.g., results of diagnostic tests, prescription information, information from specialists); use of information systems to generate quality improvement information; perceptions of patient issues with access to care; use of non-physician staff in the practice setting, practice profile information.
Relevance to The Change Foundation Work	Although this survey does not deal with the experiences of patients/clients or caregivers, it does touch on the extent of collaboration and coordination between primary care physicians and other providers, sharing of information, and physicians' perceptions about access for their patients. Analysis of results for some of the key questions may provide indications of areas of focus, and help to identify further research questions for follow-up.
Published Reports, Studies, Analyses	Numerous publications have been generated from the collected data, by the Commonwealth Fund and by partner organizations. Commonwealth Fund publications can be found through the links to yearly surveys at: http://www.commonwealthfund.org/Surveys/View-All.aspx?topic=International+Health+Policy The Ontario Health Quality Council included results from the 2009 survey of primary care physicians in the 2010 annual report, available at: http://www.ohqc.ca/pdfs/2010_report_-_english.pdf
Organization Contact for Additional Information	Ontario/Canadian partners: Heather Dawson and John Abbott , Health Council of Canada Imtiaz Daniel, Ontario Health Quality Council
References	1. 2009 International Health Policy Survey of Primary Care Doctors. Questionnaire. 2. Schoen et al. (2009). "A Survey of Primary Care Physicians in Eleven Countries, 2009: Perspectives on Care, Costs and Experiences." *Health Affairs* **28**(6): w1171-1183. 3. Phone call with H. Dawson, Health Council of Canada 4. Meeting with I. Daniel, OHQC

Survey or Research Reference	8. Cancer Care Ontario Ambulatory Oncology Patient Satisfaction Survey (AOPSS)
Sponsoring Organization(s) and Type	Cancer Care Ontario—Cancer Quality Council of Ontario, Cancer System Quality Index (CSQI) Care provider survey of patients/clients or caregivers.
Brief Description	This is a survey of patient experiences with ambulatory oncology services provided through Cancer Care Ontario. The survey tool is based on the Picker suite of tools and was validated in three provinces (including Ontario) in 2003.
Timing / Frequency	This survey has been conducted annually from 2004 through 2010. Results are reported in the following year's CQSI report.
Population Surveyed	Patients receiving outpatient services from Cancer Care Ontario ambulatory clinics.
Sample Size and Methods	Surveys were mailed out to a random sample of patients who had received ambulatory cancer services from participating cancer centres or hospitals. Sample sizes have been in the range of 1,400 per year.
Overview of Content	Six domains of care are included in the survey: • Emotional Support: the extent to which patients feel they received support for their emotional needs during care (8 questions). • Coordination & Continuity of Care: patients' assessments of the ease of transitions between different providers and settings for their cancer care (8 questions). • Respect for Patient Preferences: patients' assessments of how respectfully they are being treated (6 questions). • Physical Comfort: how well providers responded to comfort needs of patients (5 questions). • Information, Communication, Education: how care providers interact with patients and communicate information (10 questions). • Access to Care: patients' assessments of their treatment wait time and how it was handled by staff (9 questions).
Relevance to The Change Foundation Work	The survey in principle is intended to cover experiences with cancer care across a range of providers. However, these are all CCO provider organizations. There are a number of questions that relate to whether individuals felt they received adequate information about services they felt they needed; and there are questions regarding coordination and continuity of cancer care that may be adaptable to a broader range of care providers. More detailed analysis of results might provide some insight into general areas of patient concern regarding coordination of care.
Published Reports, Studies, Analyses	Results are presented annually on the CSQI website. The most recent report focused on results for emotional support as an area of concern.
Organization Contact for Additional Information	Esther Green, Provincial Head Oncology Nursing and Psychosocial Care, Cancer Care Ontario
References	1. CQSI website results and technical information. Available at: http://csqi.cancercare.on.ca/cms/One.aspx?portalId=63405&pageId=68019 2. Green, E. (2009) *Understanding the Patient's Experience in Ambulatory Cancer Care*. Presentation at Psychosocial Aspects of Cancer Symposium, March 2009. 3. Watson DE, Mooney D, Peterson S. (2007). Patient experiences with ambulatory cancer care in British Columbia, 2005/06. Centre for Health Services and Policy Research: Vancouver, B.C. 4. Sandoval GA, et al. (2006). "Factors that influence cancer patients' overall perceptions of the quality of care." *International Journal for Quality in Health Care*. 18(4):266-274. 5. Email from K. Duvalko, Cancer Quality Council of Ontario
Other Comments/Notes	The Cancer Quality Council of Ontario is rethinking how the survey is used, and are exploring new options—including the possibility of adopting new tools. Improving (including measuring) the patient experience is one of the main priorities of the upcoming Cancer Plan

Survey or Research Reference	9. Primary Care Access Survey (PCAS)
Sponsoring Organization(s) and Type	Ontario Ministry of Health and Long-Term Care Health Information/Policy Research Organization
Brief Description	This survey was initiated in 2006 in order to track population experience with access to and utilization of primary care services in Ontario. Survey data is shared with ICES and the Ontario Medical Association.
Timing/Frequency	The survey had been ongoing and continually in the field. There are quarterly waves with sufficient sample size to report results for Ontario (approximately 8,000 individuals annually). Sample size is sufficient to report LHIN level results annually.
Population Surveyed	This is a population-based survey. Some sub-groups are excluded (members of the armed forces, aboriginal reserves, institutionalized individuals).
Sample Size and Methods	Random sample, computer-assisted telephone survey. The survey is presently administered by a third party under contract to the MOHLTC.
Overview of Content	The survey contains questions primarily related to whether, where and how individuals receive various types of primary care services, along with barriers they perceive to access to primary care. Questions include, for example, whether they have a regular provider of primary care services, if not, what are the barriers and how long they have been without a regular provider, use of hospital ERs, barriers to access, etc. Respondents are also asked if they have used other health-care services (a broad range, including non-physician services) and are asked to provide health status information (e.g., presence of chronic conditions) and basic demographic information.
Relevance to The Change Foundation Work	Although there are questions related to access and barriers to care, this survey is focused on primary care utilization and there is likely little opportunity to add questions on areas of direct interest to The Change Foundation given the current length of the questionnaire. However, since January, 2007 respondents have been asked to indicate if they are willing to be contacted in the future for follow-up. It may be possible to use survey results to identify a specific population (e.g., individuals with chronic conditions or individuals that use a number of other health-care services) that could be targeted for a more detailed and specific survey. Approximately 65% of those surveyed have responded "yes" to the question and could be contacted for additional follow-up.
Published Reports, Studies, Analyses	Examples of reports from the MOHLTC include: *Access to Primary Care in Ontario, 2008* *Access to Primary Care in Ontario: A Focus on ER Utilization, 2010*
Organization Contact for Additional Information	Sten Ardal, Director Health Analytics Branch, Ministry of Health and Long-Term Care.
References	1. Current PCAS Questionnaire 2. Two sample analytical reports on results • Access to Primary Care in Ontario, 2008 • Access to Primary Care in Ontario: A Focus on ER Utilization, 2010 3. Meeting with S. Ardal and C. Hay

Survey or Research Reference	10. Canadian Community Health Survey (CCHS)
Sponsoring Organization(s) and Type	Statistics Canada (development is coordinated across a number of organizations including provincial Ministries of Health and Public Health Units, CIHI, etc.). Health Information/Policy Research Organization
Brief Description	This is general population based survey that addresses a broad range of areas related to health: general health status, access to and utilization of health services, and perceptions of the health system and services.
Timing/Frequency	This survey was conducted bi-annually from 2001 through 2007. Since 2007 there has been an annual CCHS.
Population Surveyed	The survey is directed to the general Canadian population. However, there are notable exclusions: individuals living on Indian Reserves and on Crown Lands, institutional residents, full-time members of the Canadian Forces, and residents of certain remote regions.
Sample Size and Methods	The total sample size for Canada is approximately 65,000. A sophisticated sampling frame is used to obtain representative samples across defined Health Regions. A mixture of telephone and in-person computed assisted interviewing is used, depending on the sample frame.
Overview of Content	The general content of the CCHS is quite comprehensive and is organized into a series of modules. A number of core modules have been consistent over the past few years and are administered in all regions in all provinces. Other optional modules represent content that might not be included in all areas of the country, and there are also theme modules which may vary from year to year, but which are included across the country.
Relevance to The Change Foundation Work	There are no modules (core, theme or optional) that specifically address experiences of individuals coordinating care or navigating across a number of care providers. However, analyses of results might provide a starting point to investigate patterns of utilization across many different care providers and relation to satisfaction with health services and community care services, for example.
Published Reports, Studies, Analyses	CCHS results are a widely available resource and have been used in numerous research reports, health indicator reports, etc.
Organization Contact for Additional Information	Not Applicable.
References	1. Statistics Canada, Canadian Community Health Survey, Definitions, Data Sources and Methods. Available at: http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3226&lang=en&db=imdb&adm=8&dis=2 2. CCHS 2009 Questionnaire.

Survey or Research Reference	11. Canadian Survey of Experiences with Primary Health Care (CSE-PHC)
Sponsoring Organization(s) and Type	Statistics Canada. The Health Council of Canada and CIHI have also sponsored and participated in the development of this survey Health Information/Policy Research Organization
Brief Description	The Health Council of Canada contracted Statistic Canada to conduct the first iteration of this survey, focused on access to, utilization of, and experiences with primary health care. The first iteration was conducted in 2006-07. Following this, CIHI joined the Health Council and Statistics Canada in redeveloping the survey to both expand the sampling strategy to support national and provincial estimates of results and to revise content related to barriers to access and use of health care.
Timing/Frequency	The original survey was conducted over the 2006-07 period, and supported a report on primary health care reform by the Health Council of Canada. The second iteration of the survey was conducted in early 2008. Although the survey is described as "active," there are no plans at present to conduct it again.
Population Surveyed	This was a general population-based survey of adults aged 18 and over. Individuals living on Indian Reserves or Crown lands, residents of institutions, full-time members of the Canadian Armed Forces and residents of certain remote regions were excluded.
Sample Size and Methods	The 2008 survey sample was drawn from the 2007 Canadian Community Health Survey and the strategy was designed to support reporting of national and provincial results. There were approximately 11,600 total respondents. Surveys were conducted via computer-assisted phone interviews.
Overview of Content	The survey content focuses on access to (including barriers) and utilization of primary health-care services, including emergency departments and relationships with primary care providers, along with general health status and presence of chronic conditions. There are also questions around hospitalizations and visits to a broad range of health-care providers, for example, nurses, physiotherapists, social workers, dieticians, etc. Other questions deal with perceptions of primary care follow-up after hospital admissions, sharing of information and medical records, duplication of tests and conflicting information from different providers.
Relevance to The Change Foundation Work	More in-depth analysis of responses to questions about coordination of care, coordination of follow-up appointments and exchange of information and some of the barriers identified to access to care could help to inform and define areas for more in-depth study by The Change Foundation.
Published Reports, Studies, Analyses	Health Council of Canada publications (2006-07 survey): 1. Experiences of Canadians with Chronic Conditions 2. Canadian Survey of Experiences with Primary Health Care 2007. Data supplement to *Fixing the Foundation: An Update on Primary Health Care and Home Care Renewal in Canada* CIHI publications (2008 survey): 1. Experiences with Primary Health Care in Canada
Organization Contact for Additional Information	Greg Webster, Director, Primary Health Care Information, CIHI
References	1. Statistics Canada. Definitions, data sources and methods. Canadian Survey of Experiences with Primary Health Care. Webpage available at: http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=5138&lang=en&db=imdb&adm=8&dis=2 2. Canadian Survey of Experiences with Primary Health Care Questionnaire, 2008. 3. Email from G. Webster, CIHI

Survey or Research Reference	12. National Physician Survey (NPS)
Sponsoring Organization(s) and Type	College of Family Physicians of Canada (CFPC), Canadian Medical Association (CMA), Royal College of Physicians and Surgeons of Canada (RCPSC), Canadian Institute for Health Information (CIHI) Other project
Brief Description	This is a Canada-wide survey of physicians, covering specialists as well as family physicians and general practitioners. It has been conducted in 2004 and 2007 with results released. The 2010 survey is currently in the field with results expected in spring, 2011. It addresses a broad range of information about physicians and along with their clinical practices.
Timing/Frequency	This survey has been run every three years since 2004.
Population Surveyed	The 2007 survey was mailed out to all physicians licensed to practice in Canada, developed from an NPS masterfile which was based on information from the CMA Membership System, the CFPC membership database, and the RCPSC membership database.
Sample Size and Methods	Based on information from the NPS masterfile, all physicians were either mailed a questionnaire to complete and return, or contacted via email to complete an on-line questionnaire. Response rates varied by province and specialty, but the overall rate for Canada was 32%.
Overview of Content	The main content sections deal with: demographic and education information (place of training and continuing medical education), work setting(s), patient care setting(s), perceptions on patient access to care, profile of practice, allocation of time, professional income, planned changes to practice, use of information technology, and professional satisfaction.
Relevance to The Change Foundation Work	This survey does not address patient experiences, however it does consider the provider perspective on collaboration and patient access to care. Some of the questions address perceptions of problems or issues with coordination of care with specialist physicians and other providers of health care. An analysis of responses to questions around the extent to which physicians collaborate with other providers and share information, along with perceptions of patient access to other health-care providers, might support the development of a provider perspective on patient/client or caregiver experience with coordination and navigation.
Published Reports, Studies, Analyses	The 2007 results are available at the NPS website: http://www.nationalphysiciansurvey.ca/nps/2007_Survey/2007results-e.asp Links to a large number of reports and publications can be found at: http://www.nationalphysiciansurvey.ca/nps/news/reportsnews-e.asp
Organization Contact for Additional Information	Harleen Sahota, National Physician Survey Project Manager, College of Family Physicians of Canada
References	1. 2007 National Physician Survey Questionnaire 2. 2007 National Physician Survey Methodology and Response Rates

Survey or Research Reference	13. Quality Improvement and Innovation Partnership (QIIP) Patient Engagement Activity
Sponsoring Organization(s) and Type	QIIP is an organization focused on providing quality improvement support to Family Health Teams and Community Health Centres in Ontario. Other project
Brief Description	QIIP has led projects focused on equipping Family Health Teams (FHTs) and Community Health Centres (CHCs) in Ontario with tools to develop patient engagement and involve patients in the design of practices to improve quality and patient experience. Some of this work has included focus groups of patients to better understand patient journeys through care, the needs of "typical" patients and of patients with more complex care needs.
Timing/Frequency	This work has been conducted over the past three years.
Population Surveyed	Not applicable.
Sample Size and Methods	Not applicable.
Overview of Content	There are three areas of work/projects that could potentially be of interest to The Change Foundation strategy and that were reviewed: 1. environmental scan of patient engagement strategies in order to develop a framework addressing patient engagement 2. mapping the patient experience in Primary Health Care—engaging patients and providers to identify opportunities for improving the patient journey, based on narratives developed through focus groups 3. working with FHTs and CHCs in QIIP's Learning Collaborative to promote use of tools to support components of patient experience and satisfaction in practice quality improvement.
Relevance to The Change Foundation Work	The experience developed in mapping patient journeys in Primary Health Care, developing a narrative summary of the journey and using this as a starting place for opportunities for improvement could provide groundwork for applying similar methods to the broader health-care system. Although the project involved a small number of FHTs in northern Ontario, the methods might be transferrable to other part of the health-care system. The focus groups were used to develop narrative summaries of patient journeys, which were then validated with providers and used to generate clustered themes for improvement. The framework evolving from the environmental scan of patient engagement strategies could also inform a way of thinking about patient-centredness in the broader health-care system. The framework looks at engagement strategies across the micro level (self care, physician relationships, team and office staff) through the meso level (in this case the FHT of collaborative providers), to the macro level (primary care in the community, including public health).
Published Reports, Studies, Analyses	There is a paper in preparation describing the methods and the results for project 2 (mapping the patient experience).
Organization Contact for Additional Information	Tanya Spencer, Co-Lead, Quality Improvement and Clinical Integration, Quality Improvement & Innovation Partnership (QIIP)
References	1. Phone discussion with T. Spencer

Survey or Research Reference	14. Ontario Health Centres (primary health care Community Health Centres)
Sponsoring Organization(s) and Type	Individual Health Centres in Ontario Care provider survey of patients/clients or caregivers.
Brief Description	These are surveys of patient/client experience conducted by individual health centres in Ontario to support quality improvement and meet accreditation requirements. The accrediting body is Community Organizational Health Inc. (COHI).
Timing/Frequency	This varies across centres, but in most cases the survey would be done as part of the process of preparing for accreditation.
Population Surveyed	The surveys are administered to clients of the health centres. There are currently 56 health centres that have been accredited with some additional centres currently going through the process.
Sample Size and Methods	Accreditation standards specify that there should be a minimum of 100 clients surveyed.
Overview of Content	The model survey is a fairly short one that covers the following areas: overall satisfaction, access, communication, quality, impact, and general demographic information.
Relevance to The Change Foundation Work	CHCs are required to address coordination and continuity of care and advocacy client access to needed programs and services as part of requirements for meeting accreditation standards. The relevant standards are: **Standard 2.4.3 There are processes for ensuring coordination of service**. To achieve this standard, the organization must meet two of the three indicators. 2.4.3.1 Processes ensure that staff serving the same client coordinate service (e.g., case conferences, case consultation, client coordination). 2.4.3.2 Processes ensure coordination of service with external providers/agencies (e.g., case coordination, wrap around services, discharge and/or transfer). 2.4.3.3 The organization has monitored the coordination of service and made improvements in the last three years. **Standard 2.4.4 The organization advocates for individual clients in order to improve access to needed programs and services**. To achieve this standard, the organization must meet each of the two indicators. 2.4.4.1 The organization advocates for individual clients with other internal and external service providers when necessary. 2.4.4.2 Advocacy efforts have resulted in clients receiving needed programs and services. Questions on the model client experience survey do not currently address the client experience with these standards. However, it may be possible to review CHC programs and efforts in addressing these standards to determine where there may be barriers and where there are successes.
Published Reports, Studies, Analyses	Not applicable.
Organization Contact for Additional Information	Barbara Wiktorowicz, Executive Director, Community Organizational Health Inc
References	1. Model client survey 2. COHI client satisfaction survey. Guidelines for use. 3. Email from B. Witkorowicz

Survey or Research Reference	15. Understanding and identifying target populations for system improvement
Sponsoring Organization(s) and Type	Health System Performance Research Network (HSPRN) Other project
Brief Description	This project has linked a number of administrative datasets in order to develop profiles and understand the utilization patterns and associated costs of complex patients who are "heavy users" of services across the health-care system.
Timing/Frequency	This project was a one-time study.
Population Surveyed	Not applicable. Administrative datasets to link usage across health system sectors and develop profiles.
Sample Size and Methods	Not applicable.
Overview of Content	A cohort of individuals aged 66+ that had 2 or more ambulatory care sensitive conditions (e.g., angina, asthma, diabetes), or any one of identified tracer conditions (e.g., stroke, hip fracture, pulmonary embolism). The patients were followed on discharge from an index hospitalization to determine rates of readmissions, relationships between follow-up community care and readmission, and overall system utilization and costs.
Relevance to The Change Foundation Work	It was found that primary care visits within 7 days or home nursing care visits within 1 day following discharge appeared to reduce the risk of readmission in the 7-90 day period following discharge. The calculated health system costs of caring for this cohort over the 365-day period following discharge was nearly $36,000 per patient or $1,400 million in total. Patterns of readmissions, discharges and referrals among sectors—acute inpatient, complex continuing care, home care and long-term care were also analyzed.
Published Reports, Studies, Analyses	1. Wodchis W, et al. Presentation on *Understanding and Identifying Target Populations for System Improvement*
Organization Contact for Additional Information	Walter Wodchis, Dept. of Health Policy, Management and Evaluation, Faculty of Medicine, University of Toronto
References	1. Wodchis W, et al. Presentation on Understanding and Identifying Target Populations for System Improvement 2. Email from W. Wodchis.

Survey or Research Reference	16. An evaluation of continuity of cancer care through regional supportive care networks
Sponsoring Organization(s) and Type	Research projected funded by Canadian Health Services Research Foundation, MOHLTC, Cancer Care Ontario. Principle investigator, Dr. Timothy Whelan, Supportive Cancer Care Research Unit Directed academic research
Brief Description	This research delivered and evaluated an intervention (regional supportive care networks) designed to improve continuity of cancer care through examining changes in awareness and use of supportive care services (home care, nutritional support, and social, financial and psychological counseling) of newly diagnosed cancer patients.
Timing/Frequency	The survey work was associated with the evaluation of the intervention. Patients were surveyed five times, every six months, between June 2001 and April 2003. Health-care providers (cancer specialists, nurses and primary care physicians) were surveyed once between May and September 2003.
Population Surveyed	Patients surveyed were drawn from patients newly diagnosed with breast, colorectal or prostate cancer in three regions in Ontario—Central West, East and Northwest. The sample was drawn from the Ontario Cancer Registry. The providers included cancer specialists, nurses and a random sample of primary care physicians.
Sample Size and Methods	A total of 3,300 patients were surveyed over the five surveys (ranging between 552 and 755 at each survey). The response rate varied between 65% and 72% over the five surveys), giving a total of close to 2,300 responses. Just over 400 providers responded to the survey for a response rate of 45%.
Overview of Content	The patient survey asked questions about the awareness and use of supportive cancer services. Patients were asked about their awareness and use of 46 items related to the six areas of supportive cancer care: informational, psychological, social, physical, complementary therapy and spiritual support. The provider survey assessed provider awareness of services in a similar fashion; complementary care and spiritual care were not included. The provider survey also included questions on perceptions of system changes over the previous three years. The project also included a process evaluation case study that described the implementation of regional supportive care networks.
Relevance to The Change Foundation Work	This work is focused on examining the impact of an intervention—regional supportive care networks—on patient awareness and use of cancer support services. Although this is a component of continuity of care, the questions do not examine the patient/client experience with connecting or navigating to those services. However, the results from the patient survey suggest that awareness and use of supportive services did not change over the study period and did not seem to be improved through the implementation of the regional supportive care networks.
Published Reports, Studies, Analyses	Whelan T, et al. (2003). *An Evaluation of Continuity of Cancer Care Through Regional Supportive Care Networks*. Canadian Health Services Research Foundation.
Organization Contact for Additional Information	Jonathan Sussman, Supportive Cancer Care Research Unit, Hamilton Health Sciences, McMaster University
References	1. Whelan T, et al. (2003). *An Evaluation of Continuity of Cancer Care Through Regional Supportive Care Networks*. Canadian Health Services Research Foundation. 2. Email from J. Sussman.

Survey or Research Reference	17. A Study of the Effectiveness of Specialist Oncology Nursing Case Management in Improving Continuity of Supportive Cancer Care in the Community (SONICS)
Sponsoring Organization(s) and Type	Research project funded by Canadian Health Services Research Foundation, MOHLTC, Cancer Care Ontario. Principle investigator, Dr. Jonathan Sussman, Supportive Cancer Care Research Unit Directed academic research
Brief Description	This study is an evaluation of the impact on continuity of supportive cancer care of an intervention to refer patients to a specialist oncology nurse as a case manager (Community Interlink Program).
Timing/Frequency	The study began in early 2006 and surveys of patients enrolled in the trial ended in March, 2009. Individuals eligible to participate in the trial included those recently diagnosed with breast or colorectal cancer who lived within the Interlink program area. Enrolled individuals were assessed at baseline, 4 weeks and 8 weeks.
Population Surveyed	The surveys of continuity of supportive care were administered to patients enrolled in the randomized controlled trial.
Sample Size and Methods	All enrolled patients (183) are surveyed.
Overview of Content	The survey content addresses patients' perceptions of unmet supportive care needs, continuity of care and quality of life. It also looks at the degree of acute stress following surgery and differences in uncertainty about the illness.
Relevance to The Change Foundation Work	The survey is directly targeted to evaluating an intervention to connect individuals with supportive oncology services. The number of individuals surveyed is small and results could not be generalized beyond assessing the effectiveness of the intervention. However, the survey instrument used to assess continuity of care directly examines how patients feel and their experiences with receiving support services and care across a number of providers. The results here may suggest an approach to assessing patient/client or caregiver experiences with continuity of care and could provide useful information that could be applied to other settings about whether and how the intervention works with respect to decreasing unmet needs and improving the access of individuals to supportive services.
Published Reports, Studies, Analyses	No publications yet.
Organization Contact for Additional Information	Jonathan Sussman, Supportive Cancer Care Research Unit, Hamilton Health Sciences, McMaster University
References	1. Entry on clinicaltrials.gov. Available at: http://clinicaltrials.gov/ct2/show/NCT00182234?term=SONICS&rank=1 2. SONICS instruments • continuity of care • service utilization • supportive care needs • personal characteristics • uncertainty in illness • cancer diagnosis stress assessment 3. Email from J. Sussman

Survey or Research Reference	18. Ontario long-term care residents and families survey
Sponsoring Organization(s) and Type	Ontario Health Quality Council (with input and advice from a scientific expert panel and other organizations/associations) Care provider survey of patients/clients or caregivers. Note: this survey falls into the category of surveys of clients/patients of a health-care service provider (and/or their caregivers/families), but the OHQC plays a more directive role in this work compared to some of the other provider-sponsored surveys.
Brief Description	This survey is intended to focus on the experiences of residents of long-term care home and/or their family members. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) Nursing Home tools, with some modifications for Ontario, will be used (one survey for residents and one for family members). Implementation of the tool is pending pilot testing to determine if current requirements for surveys for the long-term care compliance program can be combined with the CAHPS tool.
Timing/Frequency	Once implemented this would be a regularly administered survey, with all long-term care facilities expected to administer the survey annually to a sample of residents and/or their families.
Population Surveyed	The survey would be directed at the residents of long-term care facilities and/or their families.
Sample Size and Methods	Sample methods to be defined. The CAHPS resident tool is intended to be administered by an interviewer, while the family tool is designed for mail out/mail in responses.
Overview of Content	The resident questionnaire contains questions that primarily deal with conditions of the facility and treatment by the staff. Facility questions include cleanliness, food and security; questions related to staff include responsiveness, respectfulness, and degree of independence allowed to the resident. There is a set of questions for bedridden patients and a few questions related to overall health status and mental state, along with demographics. The family questionnaire contains questions related to experience during visits to the facility, including interactions with staff and the condition of the facility, their perceptions of how their family member is treated by the staff, responses by the facility to requests for information and/or complaints, and demographic information.
Relevance to The Change Foundation Work	There is very little content in the standard CAHPS Nursing Home surveys that would relate to the experience of patients/clients or their caregivers across providers of care. The objectives of the surveys are to support quality improvement within the long-term care facility. There is one question on the resident survey that asks "do you visit a doctor for medical care outside the home, or inside the home?" However, given that some additional questions are being added to the survey to address Ontario needs, there may be opportunities to include survey content that would deal with the process of admissions to/discharges from hospitals, emergency room visits and appropriate follow-up, access to appropriate care outside of the nursing home, etc.
Published Reports, Studies, Analyses	Provincial results from an early pilot (2008-09) in 30 long-term care institutions are reported on the OHQC website at: http://www.ohqc.ca/en/ltc_prov_results.php
Organization Contact for Additional Information	Imtiaz Daniel, Director, Research, Ontario Health Quality Council.
References	1. CAHPS Nursing Home resident questionnaire 2. CAHPS Nursing Home family questionnaire 3. Sangl J, et al. (2007) "The Development of a CAHPS® Instrument for Nursing Home Residents," *Journal of Aging and Social Policy*, 19(2):63-82. 4. Meeting with D. Imtiaz, Ontario Health Quality Council 5. Meeting with E. Patterson, Director, Quality Improvement, Ontario Health Quality Council.

Survey or Research Reference	19. Uses of the Home-Care Reporting System (HCRS) dataset
Sponsoring Organization(s) and Type	Canadian Institute for Health Information collects and manages the HCRS. Other project
Brief Description	The HCRS contains clinical, administrative and some demographic information about clients receiving home nursing care services. The Resident Assessment Instrument—Home Care (RAI-HC©) is a key component of the dataset and includes information about health and functional status measures and clinical outcomes.
Timing/Frequency	This data is collected ongoing in Ontario for all home-care clients.
Population Surveyed	The dataset covers all home-care clients in Ontario.
Sample Size and Methods	Not applicable.
Overview of Content	The RAI-HC© component of the HCRS includes significant information about the client's health status, informal caregiver arrangements, home care services provided. The assessment also includes emergency department utilization. Through client's health number this dataset can be linked to other administrative datasets such as NACRS (for emergency department and day procedure utilization), DAD (for acute inpatient admissions), OHIP billing (for physician visits), and the Ontario Drug Benefit database (for prescriptions filled for individuals over 65 years).
Relevance to The Change Foundation Work	This dataset does not include any patient/client or caregiver experience component. However, it does contain rich information on services and assessed outcomes related to health status, activities of daily living, etc. There are opportunities to link this dataset to other administrative datasets holding clinical and utilization information, as well as to the Health Outcomes for Better Information and Care (HOBIC) dataset which includes nursing assessed outcomes as well as nursing interventions.
Published Reports, Studies, Analyses	CIHI has published some reports and analyses using the HCRS dataset. Examples include: 1. Supporting Informal Caregivers. The Heart of Home Care. 2. Home Care 2007-08 Quick Stats (excel spreadsheets summarizing home care information). Additional publications can be found at: CIHI home care reports[1]
Organization Contact for Additional Information	Nancy White, Manager, Home and Continuing Care Development, CIHI
References	1. RAI-HC Assessment Form, November 2008. 2. RAI Contact Assessment Form, May 2008 (for use in emergency departments). 3. CIHI, Home and Continuing Care Clinical Assessment Protocols Information Sheet 4. Email from N. White.

Survey or Research Reference	20. Avoidable hospitalizations initiative
Sponsoring Organization(s) and Type	This is a province-wide program, initiated through the MOHLTC and being led by the OHQC Other project
Brief Description	The focus of this initiative is to reduce the number of hospitalizations that could be avoided in Ontario. There are many strategies that might be implemented to achieve this objective, but a significant component is to improve the coordination, access to, and delivery of, community-based care, both following discharges from acute care institutions to avoid readmissions and to reduce admissions for conditions that could be managed in the community.
Timing/Frequency	This project has only recently started up with a focus coming out of the introduction of the Excellent Care for All Act.
Population Surveyed	Not applicable.
Sample Size and Methods	Not applicable.
Overview of Content	Although there has been considerable work over the past few years to look at ways of reducing avoidable hospitalizations, there has been a renewed focus to plan and coordinate province-wide strategies coming out of the introduction of the *Excellent Care for All Act*. This effort is being coordinated through the OHQC and will seek to implement health system initiatives that support coordination among providers in managing patient transitions in care (e.g. hospital to home) and reducing avoidable hospitalizations.
Relevance to The Change Foundation Work	This initiative has been called "avoidable hospitalizations", but the focus on coordination among providers in managing patient transitions and on care centred around the patient imply that it is about supporting individuals in getting the appropriate care/treatment (and level of care) from the appropriate provider at the right time. The MOHLTC has suggested that the barriers to this goal include individuals having problems with accessing and understanding information about where they can get the best health care and fragmented policies and payment structures that make it difficult for providers to integrate care across the system. These concepts are directly related to The Change Foundation's current initiatives. The OHQC will be working with a number of health-care providers and partners to move ahead. However, it will be important to support a grounding of this initiative within the patient/client and caregiver experiences of getting access to coordinated care across a range of providers and ensure that any redesign emphasizes the patient experience.
Published Reports, Studies, Analyses	Not applicable.
Organization Contact for Additional Information	E. Patterson, Director, Quality Improvement, OHQC
References	None.

Survey or Research Reference	21. Health care in Canada Survey (HCIC)
Sponsoring Organization(s) and Type	The Health Care in Canada Survey Partnership (Association of Canadian Academic Healthcare Organizations, Canadian Healthcare Association, Canadian Home Care Association, Canadian Medical Association, Canadian Nurses Association, CareNet Corporation, Health Charities Coalition of Canada, Merck Frosst Canada) Health Information/Policy Research Organization
Brief Description	This is a survey of the general population and of health-care stakeholders (physicians, nurses, pharmacists and managers).
Timing/Frequency	The survey was administered annually from 1998 through 2007. It has not been conducted since 2007.
Population Surveyed	The general population survey included adults aged 18 and over. The stakeholder survey was focused on specific categories of health-care providers (physicians, nurses and pharmacists), as well as managers.
Sample Size and Methods	The 2007 survey was a telephone survey administered by Pollara. There were approximately 800 respondents included in the stakeholder survey (200 for each category) and 1,223 respondents in the general public survey (individuals working for market research firms or for the media were excluded).
Overview of Content	The 2007 survey addressed general perceptions of the health-care system in areas such as access to care, most critical health-care system problems, attitudes and values, as well as overall impressions of quality and expectations for system change, attitudes and values. It also asked for measures of support for various policy options.
Relevance to The Change Foundation Work	This was a general public and stakeholder perception survey. It focused on perceptions of the health system and level of support for various policy options. Although there are a couple of questions around support for policies that might lead to a better coordinated system, there is little else in the survey that would be useful to address the current Change Foundation initiatives.
Published Reports, Studies, Analyses	The Health Care in Canada Survey Partnership has made a number of publications, reports ad resources available on their website (http://www.hcic-sssc.ca/english/Content.aspx?l0=7&tid=7&l=0) including access to raw data for some years of the survey. As well they have provided a page that links to selected other publications in peer-reviewed and other scholarly journals that have used or referenced the HCIC results (http://www.hcic-sssc.ca/english/Content.aspx?l0=8&tid=8&l=0).
Organization Contact for Additional Information	Not applicable.
References	1. HCIC stakeholder questionnaire and results (2007) 2. HCIC general population questionnaire and results (2007) 3. HCIC summary of findings 2007 4. HCIC website at: http://www.hcic-sssc.ca/english/Home.aspx

Survey or Research Reference	22. Report Card on Health Care
Sponsoring Organization(s) and Type	Canadian Medical Association (CMA) Health Information/Policy Research Organization
Brief Description	This is a general population survey of the perceptions, attitudes and values of Canadians regarding the health-care system.
Timing/Frequency	The CMA has sponsored this annual survey since 2001. Results for the 2010 survey were released in August, 2010.
Population Surveyed	This is a general population-based survey of Canadian adults.
Sample Size and Methods	The survey was conducted by Ipsos Reid, randomly selected individuals from the Ipsos Household Panel. The survey was administered on-line. The total sample size for 2010 was 3, 483, sufficient to support reporting of some results at a regional (i.e., Atlantic Canada) and/or provincial level.
Overview of Content	The content of the survey focused on overall perceptions of the Canadian health-care system, for example, most pressing health-care issues, confidence in the system, perceptions of the quality of care and access to services, performance of the federal and provincial governments, financing of the health-care system, views on policy options, etc. For many of the questions, respondents were asked to assign a "grade" (A through E) to their assessment of performance, quality, access, etc.
Relevance to The Change Foundation Work	There is little survey content that addresses coordination of care or experiences of individuals navigating across care providers in the system. Individuals are asked to give a grade on the level of cooperation between various health-care professionals in the community.
Published Reports, Studies, Analyses	The CMA publishes an annual report prepared by Ipsos Reid.
Organization Contact for Additional Information	Not applicable.
References	1. CMA (August, 2010). *10th Annual National Report Card on Health Care*. 2. CMA (August, 2009). *9th Annual National Report Card on Health Care*.

Survey or Research Reference	23. Measuring integration of cancer services
Sponsoring Organization(s) and Type	Mark Dobrow, Cancer Services and Policy Research Unit, Cancer Care Ontario (with collaborators from a number of other organizations). Directed academic research
Brief Description	This research project looked at using a survey of providers of cancer care services to analyze and develop a measure of integration of cancer services.
Timing/Frequency	This was a one-time survey, administered in 2007 to develop the measure of cancer service integration
Population Surveyed	The survey was directed to physicians, other clinicians and administrators across a number of organizations.
Sample Size and Methods	The sampling frame was built on a variety of sources, including the CMA directory, Cancer Care Ontario's directories, and direct contact with provider organizations including CCACs and hospitals. Hospitals identified in the sampling frame included regional cancer program host hospitals, all teaching hospitals, all children's hospitals, all cancer surgery agreement/ systemic therapy agreement hospitals, all hospitals performing over 100 cancer surgeries per year. The sample included the entire population of providers and administrators at the selected organizations that had email addresses identified. Over 5,300 email invitations were sent to potential participants, with just over 2,000 responses.
Overview of Content	The survey addressed a number of areas of collaboration, cooperation and information sharing. These included, for example, perceptions of responsiveness fo requests for advice, regional coordination of resources, regional coordination of health promotion and cancer prevention/screening activities, and awareness of whom to contact for advice.
Relevance to The Change Foundation Work	This research project does not look at patient/client or caregiver experience, and although it covers a range of providers, it is focused on cancer care services. However, to the extent that providers working in an integrated system results in improved patient/ client experience, there may be some benefit in considering a similar provider survey of perceptions of integration across other health-care services.
Published Reports, Studies, Analyses	Dobrow MJ, et al. (2009). "Measuring Integration of Cancer Services to Support Performance Improvement: The CSI Survey". *Healthcare Policy*. 5(1):35-53.
Organization Contact for Additional Information	Mark Dobrow, Cancer Care Ontario
References	1. Dobrow MJ, et al. (2009). "Measuring Integration of Cancer Services to Support Performance Improvement: The CSI Survey". *Healthcare Policy*. **5**(1):35-53.

Survey or Research Reference	24. Evaluation of an intervention to improve the transition of patients between acute and community-based care
Sponsoring Organization(s) and Type	This is a research project with a number of collaborators from different institutions, including HPME (University of Toronto), Community Health Research Unit (University of Ottawa), and the Supportive Cancer Care Research Unit, McMaster University Directed academic research
Brief Description	This project includes plans for structured interviews of patients and telephone surveys of those who have received the intervention (a visit from a nurse practitioner post-discharge and possibly enhanced CCAC case management).
Timing/Frequency	This is a one-time evaluation of the intervention. It is expected that the interviews and surveys will be completed over October 2010 through March 2011, with some early results available in spring, 2011.
Population Surveyed	The survey will be directed at patients enrolled in the trial. Patients eligible for inclusion are those identified as being at high risk for readmission.
Sample Size and Methods	All patients enrolled will be interviewed or surveyed over the phone.
Overview of Content	Based on the current interview guides, individuals (patients and/or their caregivers) would be asked about how many providers they receive care from, how they feel in general about the coordination of care, an example of an experience where there was "good" coordination of care , and an example of an experience where there wasn't good coordination of care. The guide also includes questions about how the experiences made individuals feel (levels of confidence, frustration, etc.).
Relevance to The Change Foundation Work	The responses from the individuals enrolled in the study would be directly relevant to the current Change Foundation initiatives. The responses would speak to experiences of both patients and caregivers when trying to access care or obtain services from a number of health-care providers. However, although these results could provide important insight, they would apply only to those individuals specifically targeted by the intervention under study.
Published Reports, Studies, Analyses	Not applicable.
Organization Contact for Additional Information	Walter Wodchis, Dept. of Health Policy, Management and Evaluation, Faculty of Medicine, University of Toronto.
References	1. Caregiver coordination of care interview guide 2. Patient coordination of care interview guide 3. Email from W. Wodchis

Footnotes

1. Full link is http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=rel_cont_more_e&cw_rel=10395&cw_stitle=HCRS%20home%20care#Media%20Releases

APPENDIX 2. Examples of Survey Content (questions)

This list is not exhaustive, but is intended to illustrate the types of questions from some of the current surveys that would be relevant to better understanding patient/client or caregiver experience with transitions across and movement into and out of the health-care system. There may be other relevant questions in these and other survey tools. The questions listed below may be paraphrased and some response selections which are not relevant may be excluded.

CCAC Client and Caregiver Experience Evaluation Tool

- I'd like you to think back to when you first spoke to someone at the CCAC. Do you agree or disagree with the following statements (READ LIST) [RANDOMIZE] How about?
  - → I was given the information I needed about CCAC services
  - → I felt it was easy to get the services [I/NAME] needed
- I would now like you to think about the times when you have seen or spoken to [YOUR/NAME'S] [CASE MANAGER/CARE COORDINATOR]. Please tell me whether you agree or disagree with the following statement: (READ LIST) [RANDOMIZE]
  - → I [TRUST/TRUSTED] the [CASE MANAGER/CARE COORDINATOR] to look after [MY/NAME'S] care overall
  - → The [CASE MANAGER/CARE COORDINATOR] [MAKES/MADE] helpful suggestions about [MY/NAME'S] care
  - → The [CASE MANAGER/CARE COORDINATOR] [HELPS/HELPED] [ME/NAME] get the services [I/HE/SHE] [NEED/NEEDS/NEEDED]
  - → The [CASE MANAGER/CARE COORDINATOR] [SPENDS/SPENT] enough time with [ME/NAME]
- Has receiving [SERVICE NAME] from different [PROFESSIONAL NAMES]s had a positive impact, negative impact or no impact at all on the quality of care [YOU RECEIVE/YOU RECEIVED/NAME RECEIVES/ NAME RECEIVED]?
- How often [DO/DID] [YOU/NAME] need to repeat the same information to several [PROFESSIONAL NAME]S?
- Again, thinking about when the [SERVICE NAME] [YOU/NAME] received ended, did you?... [RANDOMIZE]
  - → Know ahead of time when [YOUR/NAME'S] services would end.
  - → Feel [YOU/NAME] needed other help after [YOUR/HIS/HER] services ended.
  - → Receive clear explanations about [YOUR/NAME'S] options to receive other services in the community after [YOUR/HIS/HER] CCAC services ended
  - → Feel that [YOU/NAME] received the support [YOU/HE/SHE] needed. E5. Before [NAME] was offered a place in a long-term care home, did the CCAC talk to you about other options for their care, such as a retirement home, supported housing or increasing home support from the CCAC?
- In your opinion, when the CCAC offered [NAME] a place in a long-term care home, did they?...(READ LIST) [RANDOMIZE]
  - → Explain things in a way that was easy to understand
  - → Listen to what [NAME] wanted in a long-term care home
  - → Answer all your questions
  - → Treat [NAME] with courtesy and respect
  - → Help find a home that matched [NAME'S] needs
  - → Offer enough information about long-term care homes to make a selection
  - → Cleary explain the steps involved in the long-term care application process
  - → Provide you with enough information about how to prepare for [NAME'S] move into the home
  - → Offer a choice of long-term care homes for [NAME]
  - → Offer choices for homes that met [NAME'S] cultural needs
  - → Offer choices for homes that met [NAME'S] language needs
- Overall, how satisfied or dissatisfied are you with [NAME'S] experience of moving into a long-term care facility, using a scale of 0 to 10 where 0 is very dissatisfied,10 is very satisfied, and 5 is neither dissatisfied or satisfied? You can give a rating anywhere between 0 and 10 depending on how you feel.
- [Do you] feel you could call the CCAC's [CASE MANAGER/CARE COORDINATOR] if you felt [YOU/NAME] needed help again.

NRC+PICKER ACUTE INPATIENT HOSPITAL SURVEY

Hospital Staff...

- Sometimes in the hospital, one doctor or nurse will say one thing and another will say something quite different. Did this happen to you?

Going Home...

- Did the doctors and nurses give your family or someone close to you all the information they needed to help you recover?
- Did you know who to call if you needed help or had more questions after you left the hospital?

NRC+Picker Hospital Emergency Department Survey

- Did you need further treatment after you left the Emergency Department?
- Was an appointment made for this treatment before you left the Emergency Department?
- Did you know who to call if you needed help or had more questions after you left the Emergency Department?

Primary Care Access Survey (PCAS)

Having a Regular Doctor

- Do you see any type of doctor, for your health, on a regular basis?
- Is this the same doctor you see for [identified chronic condition]?
- Do you have any OTHER FAMILY doctor, FAMILY physician, or FAMILY medical doctor?
- For individuals who do not have a family doctor, there is a series of questions exploring barriers, what the individuals might have done to try to find one, how long they have not had one, reasons why they don't have one, and what they do when they need primary care services.

Visits to Other Care Providers

- Have you seen a medical specialist over the last 12 months?
- Have you seen a physiotherapist in the last 12 months?
- What about an occupational therapist, have you seen one in the last 12 months?
- Have you seen a dietician or nutritionist in the last 12 months?
- Have you seen a podiatrists or a chiropodist in the last 12 months?
- Have you seen a mental health workers such as psychotherapists or a psychologists in the last 12 months?

Barriers to Primary Care Access

- There is a series of questions about whether individuals saw their regular doctor for primary care-related health concerns (e.g., regular check-up, care for urgent health problem, monitoring, information). If they did not, they are asked to identify the reason(s) including (among others):
  - → did not know where to go;
  - → specific type of care/service not available at time or place required.

The 2008 Commonwealth Fund International Health Policy Survey of Sicker Adults

- Last time when you needed medical care in the evening, on a weekend or on a holiday, how easy or difficult was it to get care without going to the hospital emergency department?
- Last time you were sick or needed medical attention, how quickly could you get an appointment to see a doctor?
- Is there one doctor you usually go to for your medical care?
- Is there one doctor's group, health center, or clinic you usually go to for most of your medical care?
- How long have you been [IF Q545/1 SHOW: seeing this doctor [IF Q545/2, SHOW: going to thisplace] for your medical care?
- How easy or difficult is it to contact your doctor's practice during regular practice hours by TELEPHONE about a health problem?

- When you need care or treatment, how often does your regular doctor know important information about your medical history?
- How often does your regular doctor or someone in your doctor 's practice help coordinate or arrange the care you receive from other doctors and places, such as make appointments with a specialist?
- In the past 2 years, when getting care for a medical problem, was there ever a time when…?
  - → Test results, medical records, or reasons for referrals were not available at the time of your scheduled doctor's appointment
  - → Doctors ordered a medical test that you felt was unnecessary because the test had already been done
- In the past 2 years, how often did you feel your time was wasted because your medical care was poorly organized? [INTERVIEW, ONLY PROMPT IF NECESSARY: For example, having to go to multiple places for care, providers not available at time of scheduled appointment, test results not yet available, etc.]
- When you saw the specialist or consultant, did he or she have information about your medical history?
- After you saw the specialist or consultant, did your regular doctor seem informed and up-to-date about the care you got from the specialist/consultant?
- In the past 2 years, how often have ANY of your doctors or your pharmacists…
  - → Reviewed and discussed all the different medications you are using, including medicines prescribed by other doctors?
- When you left the hospital, [INSERT ITEM]…?
  - → Did you receive clear instructions about symptoms to watch for and when to seek further
  - → Did you know who to contact if you had a question about your condition or treatment
  - → Did the hospital staff provide you with a written plan for your care after discharge
  - → Did the hospital make arrangements for you to have follow-up visits with a doctor or other health-care professional

Canadian Survey of Experiences with Primary Health Care

- Is there a place that you usually go to if you are sick or need advice about your health?
- Do you have a regular medical doctor?
- Why do you not have a regular medical doctor?
- How long have you been seeing or going to this [primary care provider]?
- How often does your [primary care provider] help you coordinate the care you receive from other doctors and places when you need it?
- Your [primary care provider] delivers a range of services that meets most or all of your primary health care needs. Do you...?
  - → agree/disagree
- After you left the hospital, did your [primary care provider] seem informed and up-to-date about the plan for follow-up care?
- Respondents asked to indicate if they have had visits with any of the following care providers in the past 12 months: family physician, nurse, physiotherapist, social worker, counsellor, pharmacist, dietician, other medical specialists
- Thinking of the most recent time you saw or talked to a specialist about your mental, emotional or physical health, did you have a follow-up appointment with your [primary care provider] to talk about those health issues?
- Thinking of that follow-up appointment, did your [primary care provider] have information or test results from the specialist?
- In the past 12 months, how often have test results or medical records not been available to your family physician (or general practitioner) at the time of your scheduled appointment?
- In the past 12 months, how often have medical tests or procedures been repeated unnecessarily because the test had already been done?
- In the past 12 months, how often have you received conflicting information from different physicians or health-care professionals?
- Reasons for experiencing difficulties accessing care (including among others)
  - → Did not get adequate info or advice
  - → Did not know where to go/call/uninformed
  - → Service not available in the area or at time required
- In the past 12 months, how often have your medical doctors reviewed and discussed all the different medications you are using, including medicines prescribed by other medical doctors?

National Physician Survey

- Please indicate with whom you regularly collaborate in providing patient care and whether your collaboration is part of a formal arrangement. Check ALL that apply.
  - → List includes specialists, NPs, allied health professionals, complementary/alternative medicine providers
- When collaborating do you. . . Check ALL that apply
  - → Consult by telephone?
  - → Discuss patients/clinical issues electronically (email, list serve, internet)?
  - → Meet together to review patients/clinical problems?
  - → Provide a consultation/opinion without seeing the patient in person?
  - → Share patient care decisions?
  - → Discuss new evidence and its applicability to your patients?
  - → Review adverse events/critical incidents together?
  - → Participate in joint educational activities?
  - → Feel this working relationship improves the care your patients receive?
  - → Feel this working relationship enhances the care you can deliver?
- What do you see as major impediments to your delivery of care to your patients? Check ALL that apply. (includes the following among others):
  - → Availability of test results
  - → Availability of relevant patient information at the point of care
  - → Poor inter-personal communications with
    - family physicians,
    - other specialists
    - other allied health professionals
- Please rate the accessibility to the following for your patients.
  - → List of many services, e.g., mental health, palliative, cancer, cardiac, hospital beds, diagnostic services, home care, drugs and appliances, allied health services)
- Indicate if you have access to and use of electronic interfaces to external laboratory/diagnostic imaging facility, hospitals/other clinics, chronic care patient registries)

3. LIST OF ORGANIZATION ACRONYMS

AAH PMO	Aging at Home Program Management Office
AOHC	Association of Ontario Health Centres
CAMH	Centre for Addiction and Mental Health
CCAC	Community Care Access Centre
CCO	Cancer Care Ontario
CFPC	College of Family Physicians of Canada
CHRU	Community Health Research Unit, University of Ottawa
CIHI	Canadian Institute for Health Information
CMA	Canadian Medical Association
CWF	Commonwealth Fund
HCC	Health Council of Canada
HCCS	Health Care in Canada Survey
HSPRN	Health System Performance Research Network
LHIN	Local Health Integration Network
MOHLTC	Ontario Ministry of Health and Long-Term Care
OACCAC	Ontario Association of Community Care Access Centres
OHA	Ontario Hospital Association
OHQC	Ontario Health Quality Council
QIIP	Quality Improvement and Innovation Partnership
RCPSC	Royal College of Physicians and Surgeons of Canada
SCCRU	Supportive Cancer Care Research Unit, McMaster University

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Read our Strategic Plan 2010, *Hearing the stories, changing the story*

THE CHANGE FOUNDATION

The Change Foundation is an independent policy think tank, intent on changing the health-care debate, health-care practice and the health-care experience in Ontario. It leads and leverages research, policy analysis, quality improvement and strategic engagement to enable a more integrated health-care system in Ontario designed with individuals and caregivers top of mind.

VISION

To be Ontario's trusted advisor advancing innovative health policy and practice.

GOAL

- To improve the experience of caregivers and individuals as they move in, out of, and across the health-care system over time.
- The Foundation will adopt a participatory approach to the following four methods: research, policy analysis, quality improvement, and engagement.

MISSION

- To make caregivers and individuals in need of health care part of the health-care discussion about how to find solutions to improve their experiences.
- To stimulate new ways of thinking, behaving, and interacting to foster improved health care for people, especially when they are in transitions.
- To generate robust and independent research and policy analysis of health-care issues related to improving the experience of individuals and caregivers as they navigate the health-care system.
- To lead informed discussion and strategic engagement with the stewards, stakeholders and users of the health-care system.

MANDATE

To promote, support and improve health and the delivery of health care in Ontario.

VALUES

Excellence. We strive for excellence in all we do. **Innovation**. We take innovative approaches in developing new ideas. **Collaboration**. We work in partnership with others to achieve success. **Inclusivity**. We strive to include all voices and views.