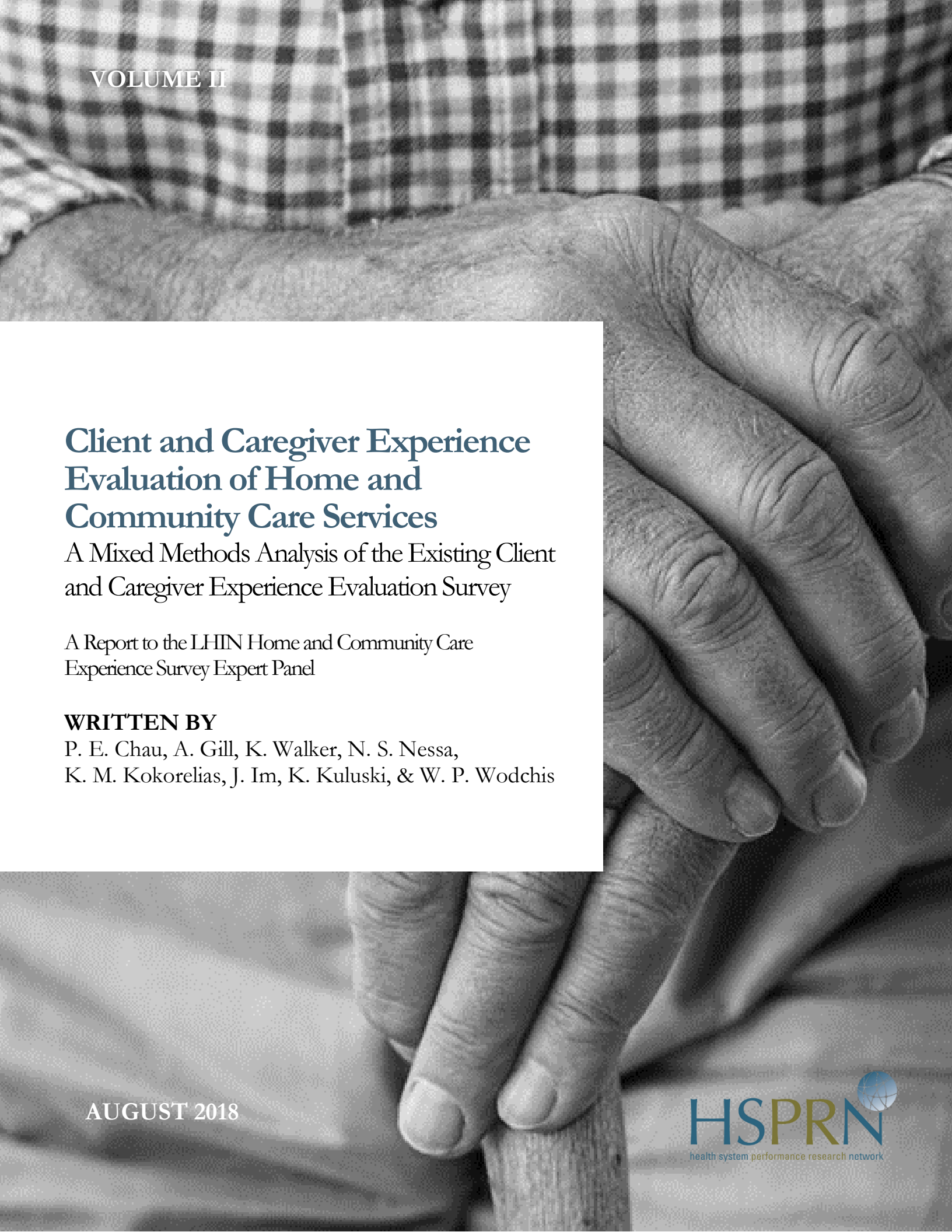

VOLUME II

Client and Caregiver Experience Evaluation of Home and Community Care Services

A Mixed Methods Analysis of the Existing Client and Caregiver Experience Evaluation Survey

A Report to the LHIN Home and Community Care Experience Survey Expert Panel

WRITTEN BY
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HSPRN
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Volume II
Client and Caregiver Experience Evaluation of Home and Community Care Services:
A Mixed Methods Analysis of the Existing Client and Caregiver Experience Evaluation Survey

The Health System Performance Research Network (HSPRN) is a multi-university and multi-institutional network of researchers who work closely with policy and provider decision-makers to find ways to better manage the health system. HSPRN consists of scientists, visiting scholars, post-doctoral fellows, graduate students, and research associates. HSPRN is recognized for its research on individuals with complex health and social care needs, its' commitment to performance measurement and its' rigorous developmental evaluations of quality improvement efforts focused on improving health outcomes, experience of care and costs for patients in Ontario's health system. The network has expertise in many areas of health system performance measurement, including clinical quality, financial management, and patient safety and experience. Academic disciplines represented include health economics, epidemiology, finance, health informatics, health services research, nursing, organizational management, and statistics.

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KEY MESSAGES

Importance of the issue

Capturing home and community care (H&CC) experiences of clients and caregivers is necessary in order to improve client-centred care. Ontario currently surveys more than 25,000 H&CC clients in each year to ascertain their experience and to monitor and to manage home care service delivery. However, the existing Client and Caregiver Experience Evaluation (CCEE) survey may have gaps that should be addresssed. The survey also does not consider the needs and experiences of caregivers who dedicate their time to supporting H&CC clients. This has prompted a quantitative and qualitative evaluation of the existing survey responses to determine performance and design features that may be improved and/or leveraged towards the development of new surveys for clients and their caregivers.

Methods

This report summarizes a quantitative and qualitative analysis of the existing CCEE survey using three years of data collected in Ontario between 2014 and 2016. Survey completion rates, response item distributions, factor and correlational analyses were all completed in addition to a qualitative analysis of a purposive sample of qualitative survey comments. The analyses were directed to answer a predetermined set of questions posed at the the outset of this project.

Findings

Findings are summarized here directly in response to key questions asked by Health Quality Ontario with respect to the existing instrument:

Q1. What is the average rate of completion of the CCEE survey?

- Clients and caregivers completed an average of 94% of the questions that they received suggesting that the existing survey is not difficult to comprehend and the burden of response may be minimal.

Q2. What percentage of survey respondents selected the most positive response option for each question? What percentage of individuals selected the most negative response option?

- Responses to most questions, except the global ratings of the delivery and organization of services, were highly positive overall, suggesting insufficient discriminant validity and that key elements of the home and community care experience may not be captured by the existing survey. Specific distributions are included in the report.

Q3. What was the variation in responses between clients of different demographic groups (age, sex, location of residence) and health status? What was the variation in responses between proxy and non-proxy respondents? What was the variation in responses between Local Health Integration Networks (LHINs) and between services providers within each Network?

- Minor variations in responses were exhibited across demographic groups, but caregivers and adult short stay clients rated some questions more positively. Conversely, clients of Chinese, Japanese, and Korean ethnicity tended to rate questions more negatively compared to other ethnic groups.
- Responses to questions did not vary between LHINs and most questions did not vary between providers within Networks.

Q4. Which questions are redundant and may be removed to reduce respondent burden?

- Correlational analyses did not suggest that any questions are redundant, and therefore should not be removed to improve the efficiency of survey administration and decrease respondent burden.

Q5. How did each of the key indicators for H&CC perform?

- Each of the nine key performance indicators demonstrated excellent performance with highly positive ratings overall. The nine key performance indicators being:
  - Overall satisfaction with LHIN, care coordinator, and service provider agency;
  - Information provided to clients/caregivers and involvement of client in developing care plan;
  - Patient-centred appointments;
  - Understanding and addressing needs;
  - Building relationships and trust;
  - Linking to other services;
  - Willingness to recommend LHIN;
  - Overall satisfaction relative to expectations and
  - Support for safety concerns

Q6. Which H&CC experience domains are captured by the existing survey?

- Exploratory factor analysis revealed two domains that are reflected in the existing survey: 1) "Delivery of home care services by provider agency"; and 2) "Interactions with the care coordinator".

Q7. Does the existing survey demonstrate validity and reliability?

- Construct validity and reliability was demonstrated for questions in both of the domains identified through factor analysis.
- H&CC clients who completed the CCEE survey, respondents were mostly female, between the ages of 19 to 64, and were on adult, chronic caseloads of H&CC services.

Q8**.** Are there relevant questions about the H&CC experience that are missing from the existing survey?

- Open-text comments revealed a number of challenges they experienced while receiving care, representing topics not sufficiently covered by the existing instrument:
  - Lack of *sufficient home and community care* with limited visits and hours of support, long wait times for receiving care, and increasing out-of-pocket expenditures to mitigate unmet needs.
  - Clients and caregivers interacted with multiple providers and *staff*, who were inconsistent, not always attentive to the client's care and needs, required greater training and expertise, and could have been more personable and caring in how they provided care.
  - Managing care within the current *organization* of the H&CC *system*, was challenging when coordinating across different agencies, providers and programs. Many providers were not always responsive to unmet needs, leading to increased confusion about their roles, and who was truly responsible for specific tasks.
  - With challenges in coordinating and accessing care, *communication* was another challenge as it was difficult to reach and speak to providers directly, resulting in clients and caregivers being uninformed. Clients and caregivers were also unsure of where to go for information and resources, what services were available, and what to expect from providers and the broader H&CC system.

Conclusion

While a number of items are useful and there is little duplication amongst the items, there is some evidence that the existing instrument offers little discriminant validity. Revisions to the current CCEE survey

has the potential to capture a more fulsome understanding of the client and caregiver home care experience. Understanding how other jurisdictions and researchers have assessed experience amongst H&CC clients and caregivers may provide a useful indication of how to enable a broader assessment of such experience. Engaging clients and caregivers in this design would also supplement a review of the instruments that are used to measure H&CC client and caregiver experience.

ACRONYMS & ABBREVIATIONS

CCAC	Community Care Access Centre
CCEE	Client and Caregiver Experience Evaluation
CCM	Client Care Model
CE	Central East
CENT	Central
CHAM	Champlain
CW	Central West
ESC	Erie St. Clair
H&CC	Home and Community Care
HNHB	Hamilton Niagra Haldimand Brant
HSPRN	Health System Performance Network
KPI	Key performance indicator
LHIN	Local Health Integration Network
LTC	Long-term care
MAPLe	Methods for Assigning Priority Levels
MH	Mississauga Halton
MLAA	Ministry-LHIN Accountability Agreements
NE	North East
NSM	North Simcoe Muskoka
NW	North West
PSW	Personal Support worker
SE	South East
SW	South West
TC	Toronto Central
WW	Waterloo Wellington

INTRODUCTION

Seniors are a rapidly growing segment of the Canadian population which presents challenges for many different parts of the healthcare system, particularly the home and community care (H&CC) sector as the delivery of services shifts away from institutional-based care settings. Recently, the Ontario Ministry of Health and Long-Term Care released the *Aging with Confidence: Ontario's Action Plan for Seniors* report which outlined the vision of making the province "a place where seniors feel supported in living independent, healthy and active, safe and socially connected lives" [1]. Delivering the optimal level of care that meets the needs of seniors in their homes contributes to realizing this goal given that over 90% of adults in the province aged 65 years and older reside in a private household, many of whom value the ability to live independently [1,2]. Consistent with the current trend of client (i.e., patient)-centred care, there is also a growing focus on the care experience of H&CC clients. Understanding their experiences along with those of the informal caregivers and non-healthcare providers will better shape the development of this sector in the future.

Information on the experiences of H&CC clients is currently being captured by the Client and Caregiver Experience Evaluation (CCEE) survey in Ontario, but it is not done so optimally. Much of this is because the purpose of the survey is to assist the Community Care Access Centres (CCACs), which are now part of the Local Health Integration Networks (LHIN), in managing their contracts with service providers. Moreover, the CCEE survey's design does not strongly account for the aspects of quality of care that clients value most. Similarly, the needs and experiences of informal caregivers, who dedicate their time to supporting these clients alongside formal paid caregivers, are not adequately reflected amongst the questions in the survey. The consideration of caregivers' experiences is needed as they carry a substantial burden in caring for clients [3]. It is necessary then to examine the existing CCEE survey to assess its strengths and weaknesses to support any revisions that might be required to better capture the experience of care of clients and caregivers.

To this end, a multi-organizational partnership was established between Health Quality Ontario, Health Shared Services Ontario, and the Health System Performance Research Network (HSPRN) for redeveloping H&CC experience surveys for both clients and caregivers. HSPRN has specifically been tasked with performing the following four key contributory tasks:

1. Quantitative and qualitative analyses of the existing CCEE survey;
2. Environmental scan of existing client and caregiver experience measures in the H&CC sector;
3. Rapid literature review of existing client and caregiver experience measures in the H&CC sector; and
4. Development of a revised survey through client and caregiver engagement sessions.

This report presents the findings from the quantitative and qualitative (also known as mixed methods) evaluation of the existing CCEE survey.

The first section briefly describes the elements of the survey tool and the sampling methodology. The second describes the demographic and health characteristics of the clients surveyed. The third section highlights the completion rate of the survey and the distribution of responses to questions. Next, the findings from an exploratory factor analysis, which aimed to identify the constructs or domains that are currently being measured by the survey, are presented. Finally, there is a qualitative analysis of the open-ended comments provided by clients and caregivers from which insights were drawn on those aspects of the care experience that are not already captured by questions on the existing survey.

DESCRIPTION OF THE CCEE SURVEY

Client Population Sampled

The CCEE survey was developed in 2008 by Ipsos to collect information on the provision of H&CC services in Ontario [4]. The survey is administered in three-month intervals to thousands of active or previously discharged home care clients who received services including nursing, personal support, and therapeutic

supports from contracted service providers. Survey recipients are sampled through stratified random sampling by service type, service provider, and/or CCAC/LHIN. Recipients of in-school, respite services, end-of-life, and convalescent care do not take part in the survey. Informal caregivers or non-healthcare professionals who provide unpaid support to clients may respond on behalf of clients [3,5].

Features of Healthcare Delivery Addressed by the CCEE

CCEE survey questions address a broad range of topics inclusive of services provided by LHINs including the intake process of assessment, care coordination, post-hospital discharge planning, placement in a long-term care (LTC) home, and clinic nursing services, as well as the provision of home care services by contracted service provider agencies. There are five global ratings or summary measures that gauge client and caregiver's ratings of the quality care coordinator, and service providers as well as of care overall (and relative to their expectations). At the end of the survey, clients and caregivers are asked demographic and service alert questions, in addition to an open-ended question on how the quality of care can best be improved. Table 1 provides examples of features of healthcare delivery that are reflected by questions within each section of the survey.

Not every section of the survey is administered to all respondents. For example, all respondents are asked eight questions about the LHIN, but only those who were recently admitted to home care respond to questions about the intake and care planning process. For this quantitative analysis of n=93,774 clients and caregivers, for the 2014-2016 fiscal years, most individuals responded to questions about the quality of care from their service provider (n=87,720), whereas fewer answered questions about recent intake (n=47,187), post-hospital discharge (n=1,200), client discharge from home care (n=30,827), LTC placement (n=2,840), and clinic nursing (n=2,267) questions.

Types of Questions and Response Format

The CCEE survey contains a combination of 72 close-ended questions including binary (i.e., "yes", "no"), Likert-scale (e.g., "strongly disagree", "disagree", "neutral", "agree", "strongly agree", etc.), and an open-ended question (Appendix A).

Survey Administration

Interviewers administer the CCEE survey via telephone with computer-assistance. The survey is available in thirteen different languages including Arabic, Chinese (Cantonese and Mandarin), French, Greek, Italian, Polish, Portuguese, Punjabi, Russian, Tamil, Urdu, and English. Sixty-five percent of respondents (n=60,869) stated their preference to complete the survey in English and 8.5% (n=7,971) another language[1]. The survey was completed in English for 95% of respondent; only 5% of individuals completed the survey in a preferred language that was not English. The most commonly requested languages were French, Italian, and Cantonese for those individuals who stated their preferred language (Appendix B).

[1] The remainder of the clients and caregivers were missing data on preferred language of the survey.

Table 1. Examples of features of healthcare delivery that are reflected by questions within each domain

Domain	Number of questions in section	Examples of features of healthcare delivery
Lhin	8	▪ Communication with the LHIN
Recent Intake Process	7	▪ Client involvement (development of care plan) ▪ Client-centredness (appropriateness of care plan) ▪ Provision of health information
Care Coordinator	10	▪ Affiliation with care coordinator ▪ Client-centredness ▪ Coordination of services within community ▪ Communication with care coordinator ▪ Safety concerns
Service Provider Agency	16	▪ Access to services ▪ Client-centredness ▪ Communication with service providers ▪ Efficiency (time) ▪ Safety concerns
Client Discharge from Home Care Services	4	▪ Communication with service provider (notification of discharge) ▪ Coordination of services within community
LTC Placement	7	▪ Access (availability) of LTC beds ▪ Client-centredness ▪ Communication with LHIN ▪ Provision of health information
Clinic Nursing Services	9	▪ Safety of facility; hand hygiene ▪ Communication with service providers ▪ Continuity of care with provider team
Hospital Discharge	6	▪ Coordination of services within community ▪ Medication ▪ Primary care access
Demographics/Health Status	2	▪ Ethnicity ▪ Self-reported mental and physical health
Open Comment	1	▪
Service Alert	2	▪ Expressed concerns that necessitate follow-up
Total	72	

Note: Intake questions (N=3) are also included in the survey.
Abbreviations: LHIN=Local Health Integration Network; LTC=long-term care.

CHARACTERISTICS OF THE CCEE SURVEY RESPONDENTS

As Figure 1 shows, the Hamilton Niagra Haldimand Brant (HNHB) LHIN had the largest number of respondents (n=10,160 [11% of total sample]). The LHIN with the fewest clients sampled was the North West (NW) (n=3,174/93,774 [3% of the total]).

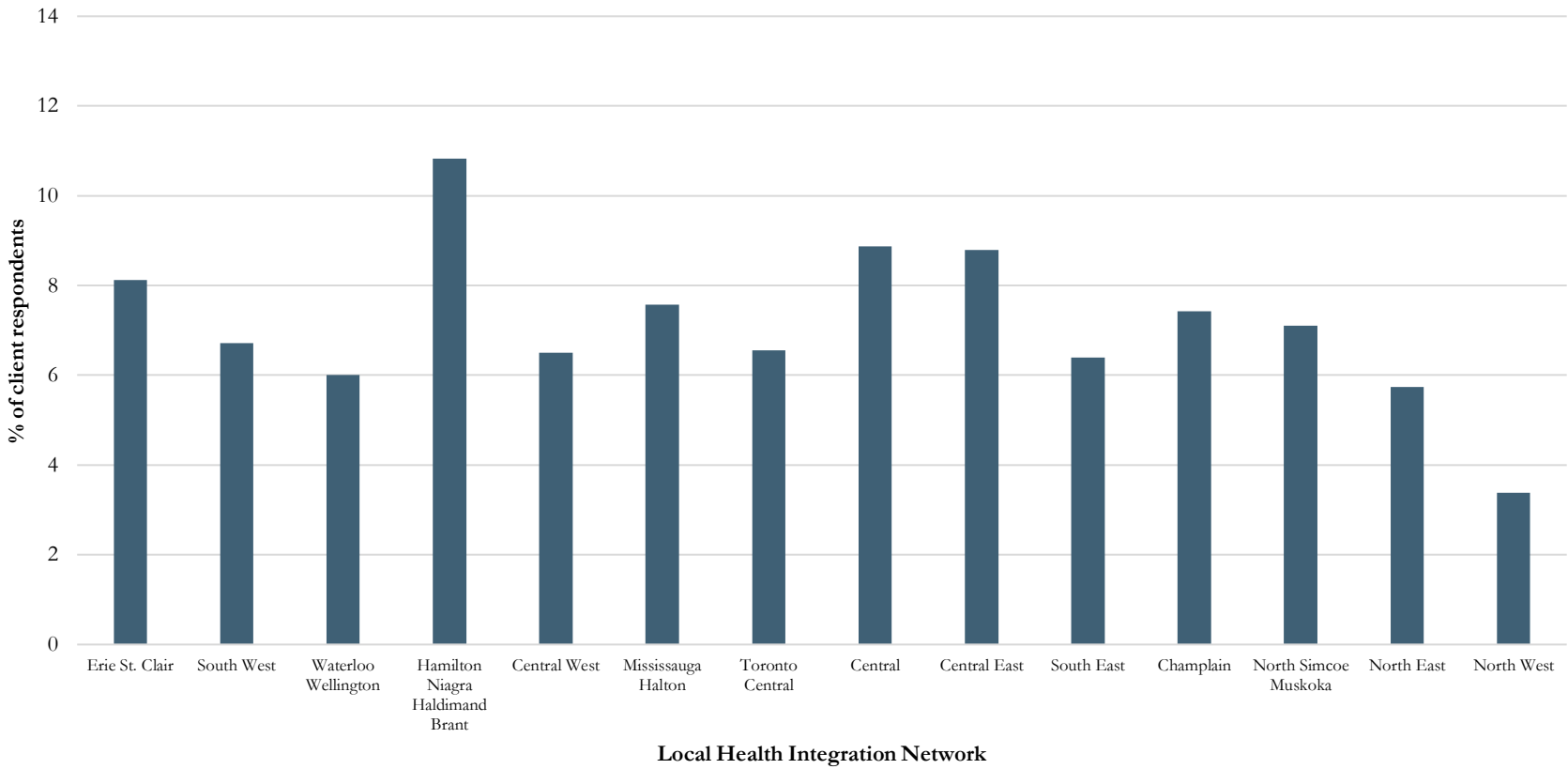

Figure 1. Representation of each LHIN in respondent sample

Approximately two-thirds of clients surveyed were 65 years of age and older in the full sample. Figure 2 shows that this varied by LHIN: seventy-five percent of clients in the Central (CENT) LHIN were seniors compared to approximately 62% in the Central East (CE), North West (NW), and Erie St. Clair (ESC) LHINs.

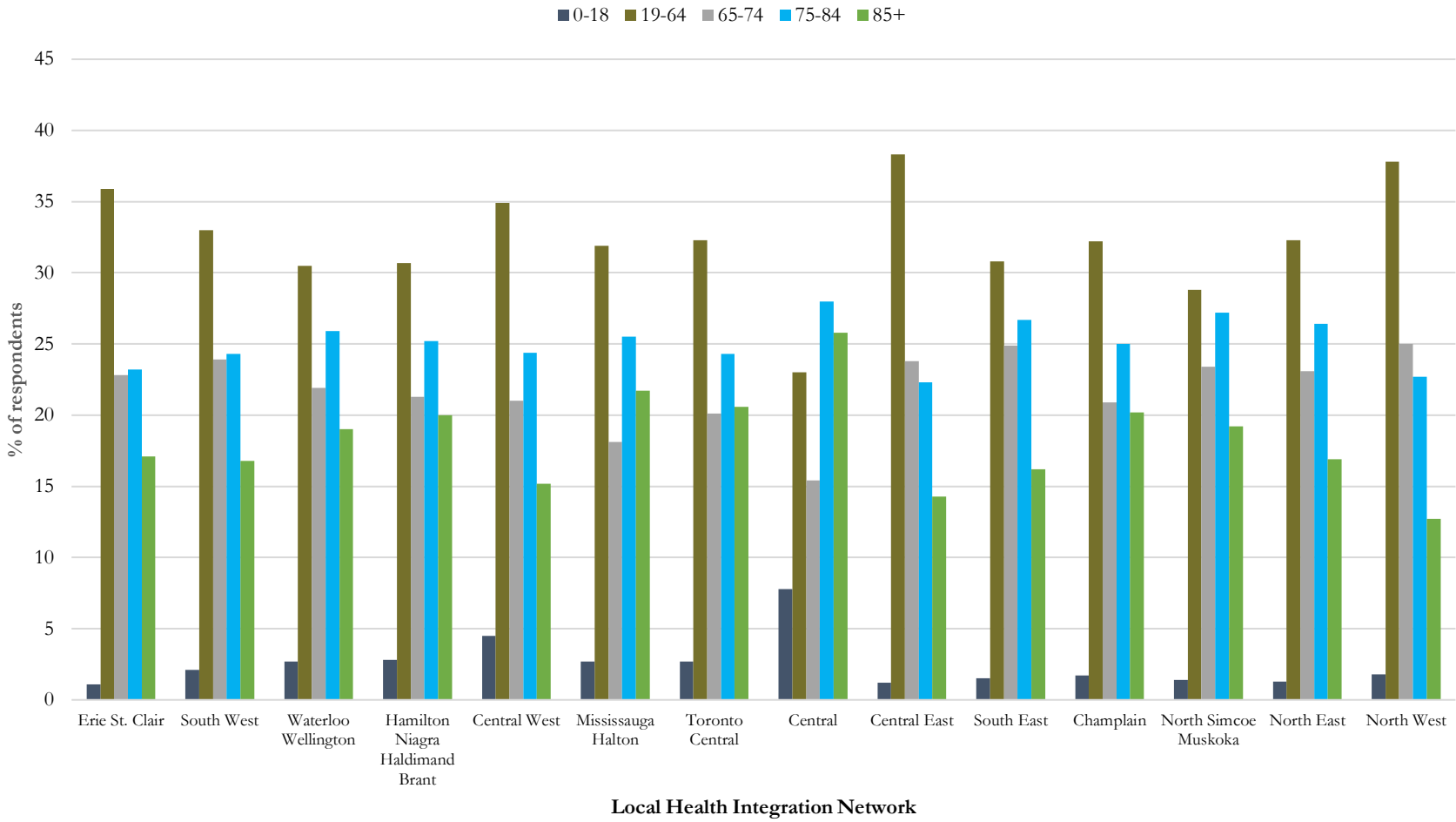

Figure 2. Age Groups of home care client CCEE respondents from each LHIN

Figure 3 shows that around 60% of client survey respondents were females in each of the LHINs.

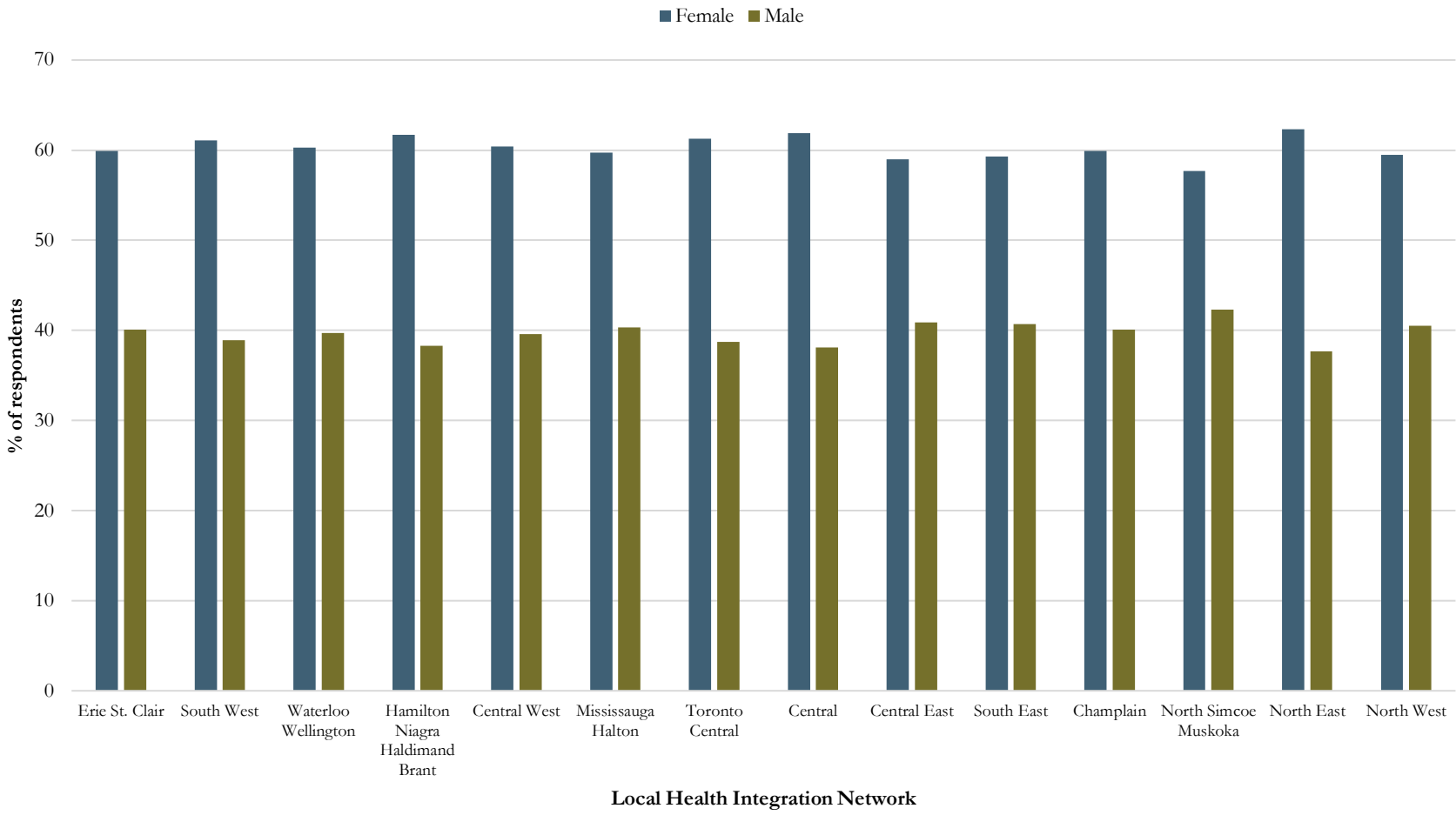

Figure 3. Sex of home care client respondents from each LHIN.

The majority of client survey respondents (60%-99%) reside in an urban location, as shown in Figure 4. South East (SE) LHIN had the highest concentration of rural-dwelling clients, whereas Central West (CW), Mississauga Halton (MH), and Toronto Central (TC) consist of mainly urban-dwelling clients.

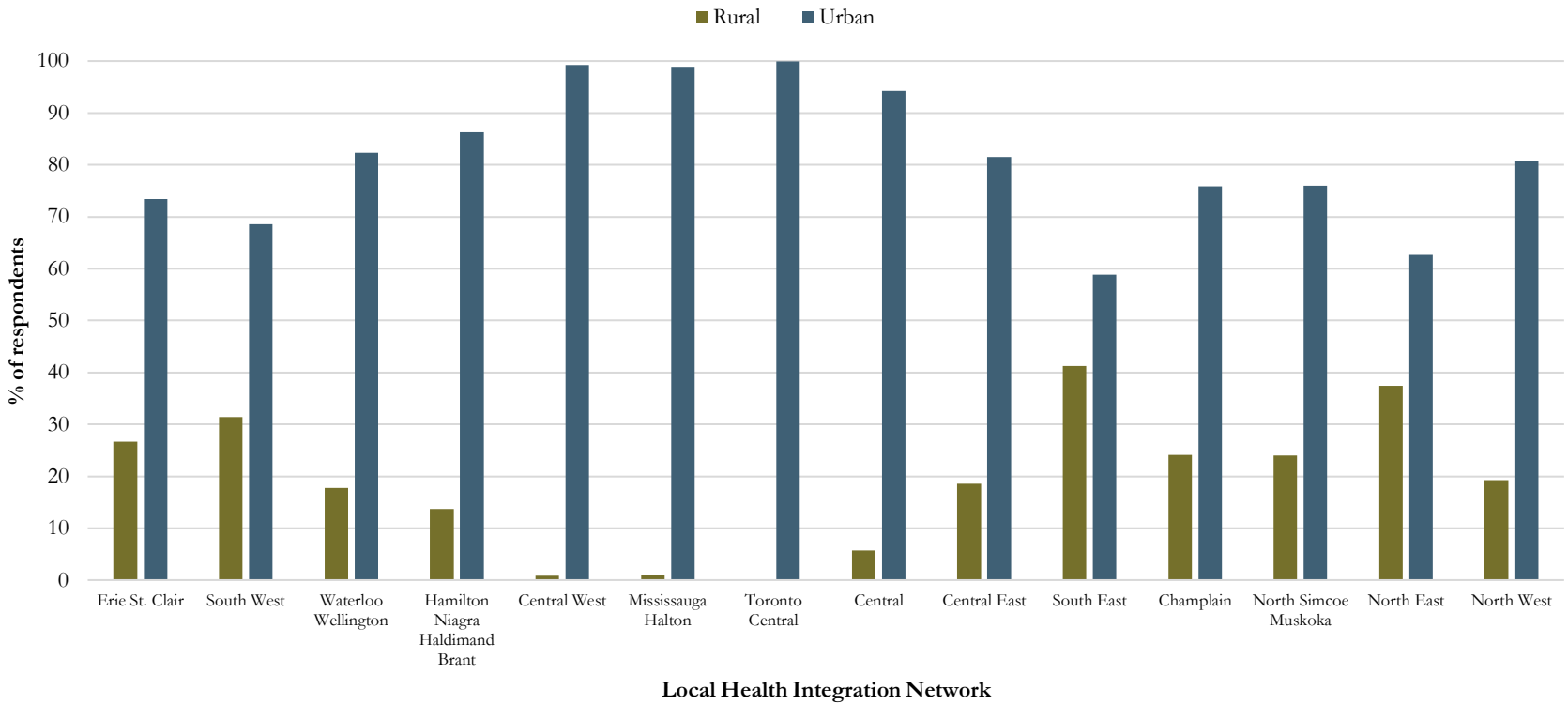

Figure 4. Residence location of home care client respondents from each LHIN

Most of the client respondents were of White ethnicity, as shown in Figure 5. With the exception of the CW, MH, TC, CENT, and CE LHINs, there was minimal ethnic diversity among the clients surveyed.

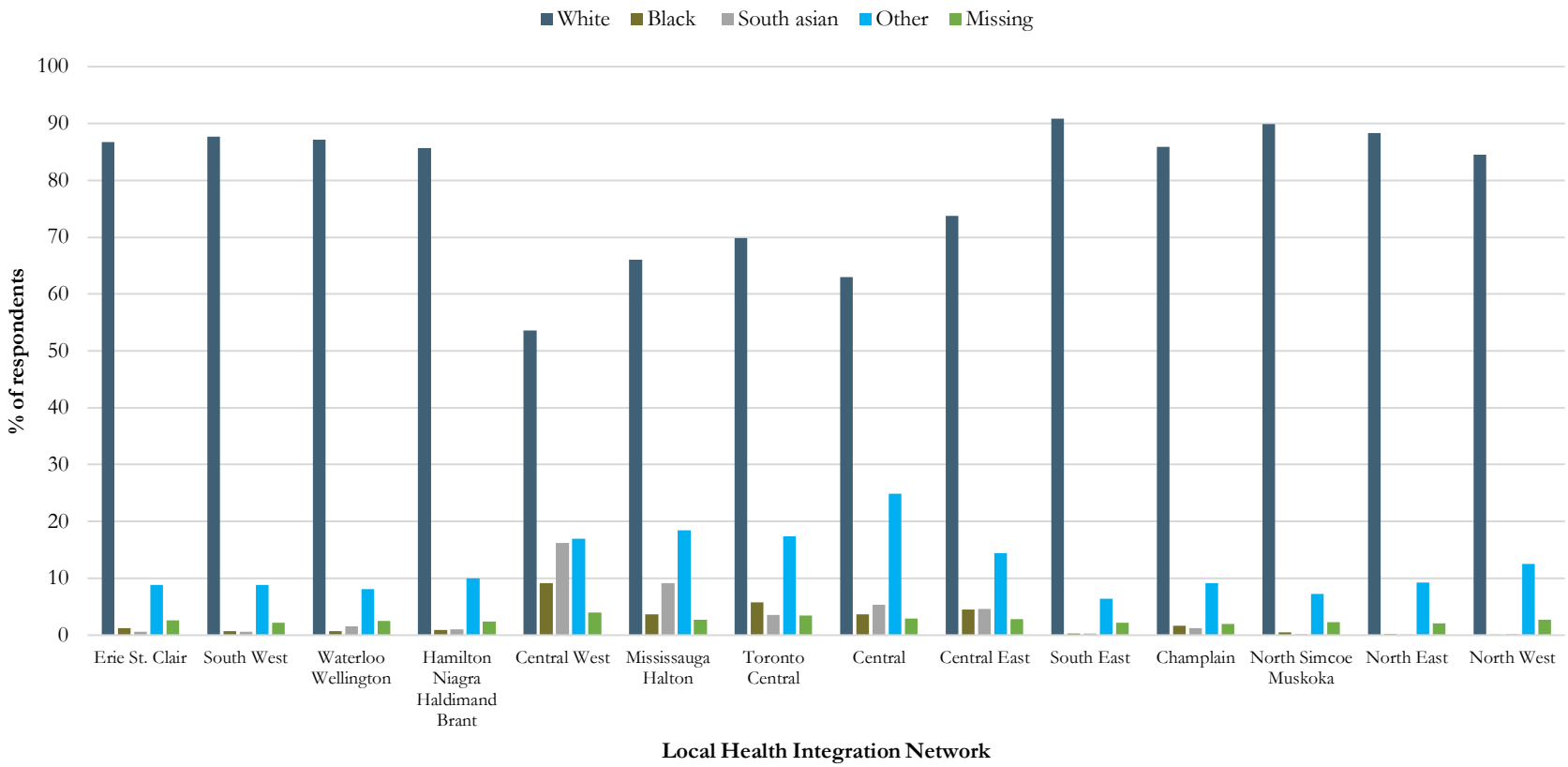

Figure 5. Ethnicity of home care clients surveyed from each LHIN.[2]

[2] "Other" ethnicities included Latin Americans, Southeast Asians (Filipinos), West Asians, East Asians (Chinese, Japanese, Koreans), Arabs, Inuit, North American Indians, Métis, and not specified.

Care coordinators consult the Client Care Model (CCM), a population-based framework that classifies individuals according to their health and socioeconomic status into one of five categories: 1) Well; 2) Short-Stay; 3) Community Independent; 4) Chronic; or 5) Complex, as a means of determining the intensity of services that are appropriate for clients [7]. Figure 6 shows that approximately 35% of the clients in each LHIN were considered chronic, with a similar percentage classified as short-stay. ESC LHIN had the largest percentage of short-stay clients, with 55% of individuals classified as such. No clients from Waterloo Wellington (WW) LHIN were classified under the CCM. This was consistent for clients surveyed in each fiscal year.

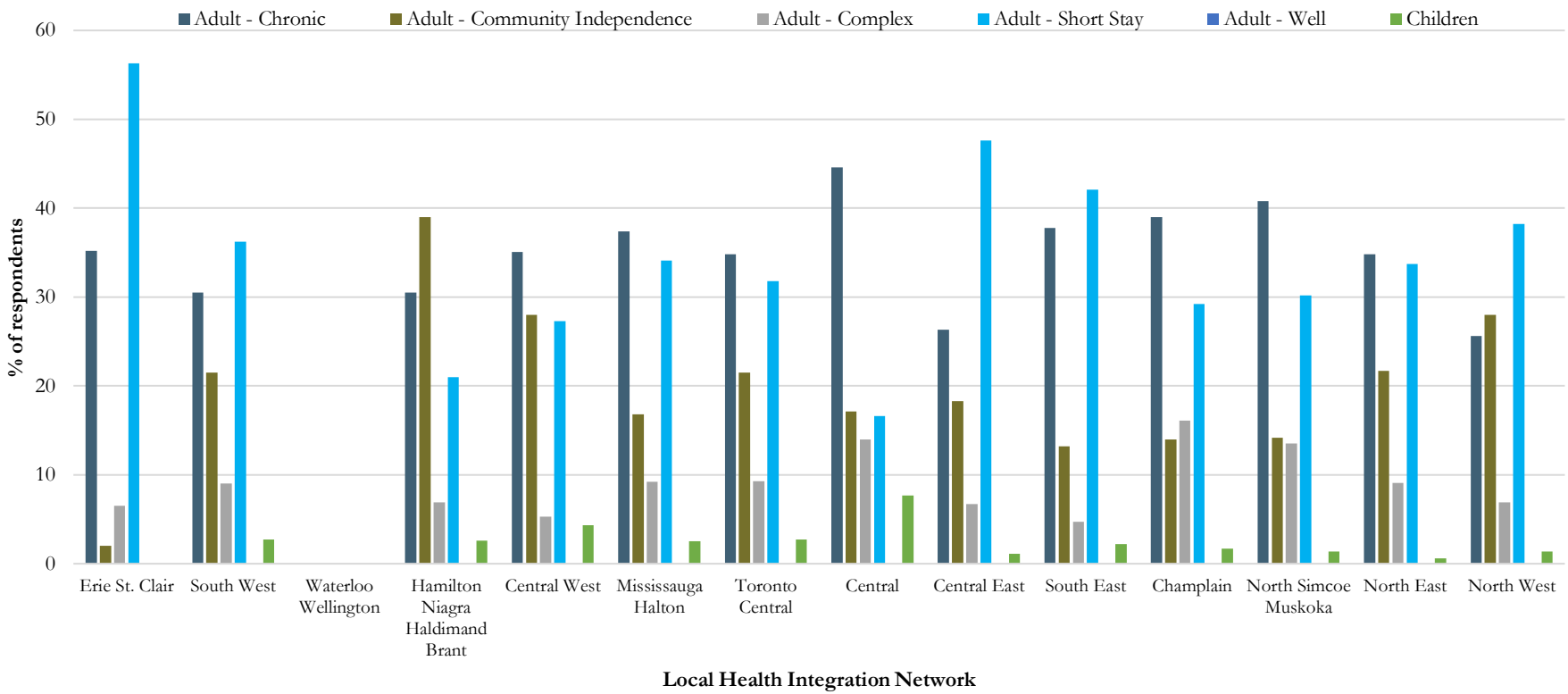

Figure 6. Classification of clients according to the CCM

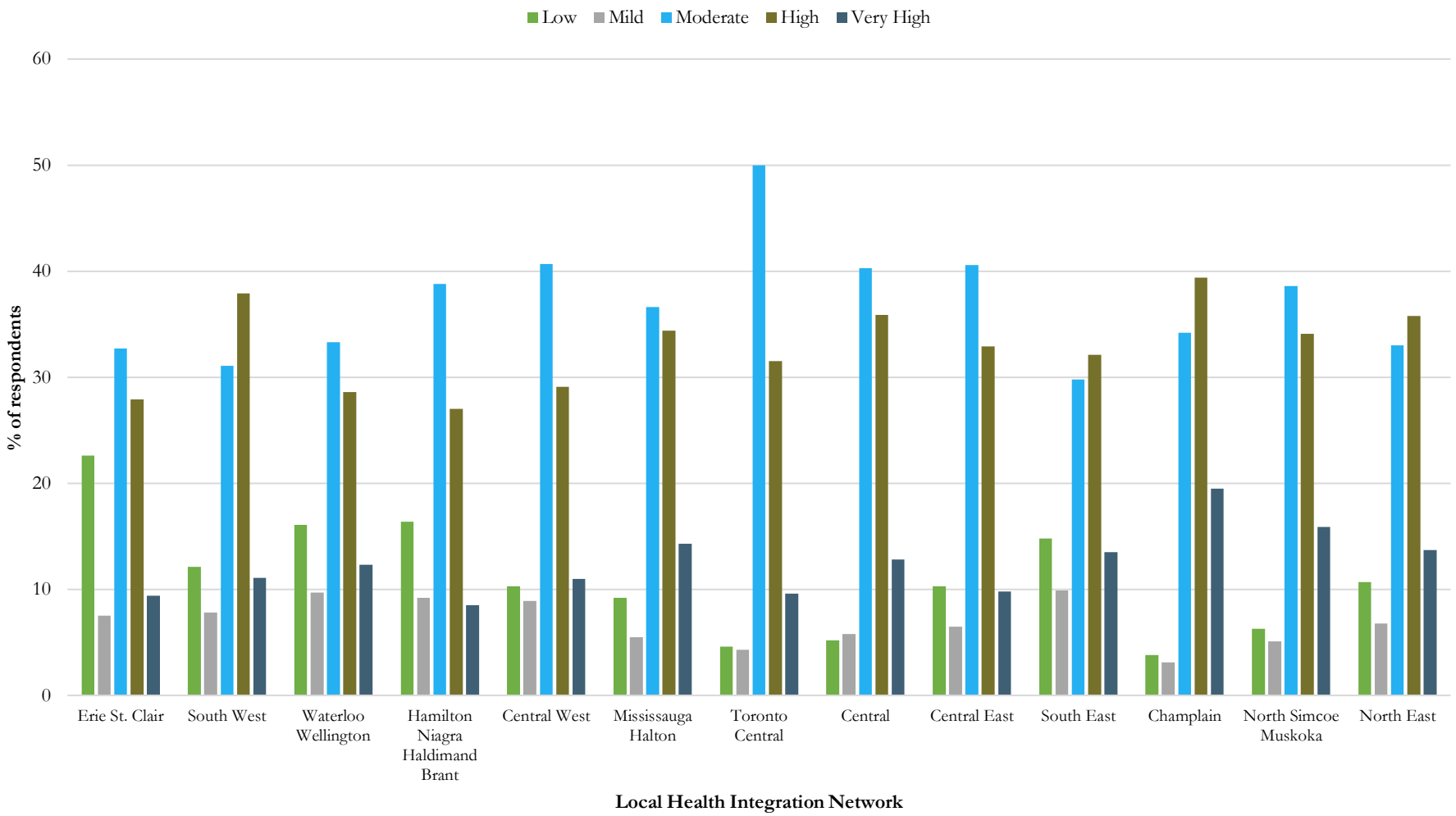

Figure 7. Risk of placement in a LTC home according to the MAPLe score.

Home care has several important aims, but most notably, it keeps clients in their communities, in the comfort of their own homes, and prevents costly institutionalization [6]. Identifying high needs individuals who are eligible for LTC is achieved with the Methods for Assigning Priority Levels (MAPLe); an algorithm based on the presence of disability impairment, cognitive impairment, behaviour disturbance, decision-making capacity, problems with medication management, ulcers, environmental challenges, falls, inadequate meals, problems with meal preparation, and difficulty swallowing [8]. Thirty-five to 60% of clients were at either a high or a very high risk of being placed in an LTC facility on average, but are instead receiving home care and continue living in the community, as shown in Figure 7 above. This suggests that service providers are able to maintain clients in the community at high levels of need.

COMPLETION RATE OF THE CCEE

Combinations of Questions Administered

Clients and caregivers who were contacted to respond to the CCEE survey received one of 14 different combinations of questions in addition to common items that probe their overall experiences with their LHIN and care coordinator (Table 2). Overall, 40% of individuals were asked questions about the contracted service provider(s) that delivered their home care services. Twenty-five percent of clients completed questions about their initial intake process when they first contacted the LHIN about needing care, their service provider(s), and the discontinuation of home care services; 19% had intake and service provider(s) questions only.

Average Completion Rate

The rate of completion of questions was excellent (Appendix C). Clients and caregivers responded to an average of 94% of the questions that they were administered, across each combination (Figure 8). This suggests that the difficulty of understanding the questions with the chosen wording and/or the burden of response to the survey may be minimal [9,10]. A notable exception is the group of individuals that were only asked questions about the continuation of H&CC services post-hospital discharge. They completed 82% of their questions on average due to missing responses to a question regarding the explanation of medications by a provider.

Average Completion Rate by Demographic Group

Rates of completion of the questions in each combination was excellent across clients of different ages, sex, residence location, and health status (long-stay, short-stay, and risk of institutionalization) (results not shown). Older clients completed fewer questions than younger individuals did, but the difference was marginal. Clients living in rural areas completed fewer questions on the post-discharge process (72%) compared to those residing in urban areas (83%).

Conditional Branching Questions

The analysis of the present survey and determining completion rates highlighted a number of challenges in identifying which questions should have been presented to the client respodents. Some recommendations here highlight the value of simplifying the survey implentaion for analytical purposes. For the design of the new CCEE surveys, it should be noted that the use of conditional branching questions might lead to the preventable loss of information on the quality of services. The current survey contains several such questions. Those who responded "No" to questions Q07 and Q07b (remember someone talking about what care was needed), Q16 (knowledge of care coordinator), Q25 and Q26 (received services from provider agency), and Q02a (H&CC services started/re-started in the last few weeks) would not have received the follow-up related experience questions in the corresponding sections. Between 68 and 27,115 individuals were not asked about questions about the intake process, service providers, and/or their care coordinator because they were unable to remember the name of their coordinator or whether certain aspects of their care took place. It is

possible to improve upon Q25 and Q26 by specifying exactly how far back in time respondents should focus on in retrospect so they may determine whether they received a service to aid their memory. Other conditional branching questions should be modified or removed to mitigate the non-collection of potentially insightful data. However, it should be noted that 116 individuals still responded to care coordinator questions despite indicating that they did not know the name of the coordinator.

Table 2. Combinations of questions administered to clients and caregivers from the CCEE

Combination	n	%
Service provider agency	37,166	39.63
Client discharge & recent intake & service provider agency	23,450	25.01
Recent intake & service provider agency	17,946	19.14
Client discharge & service provider agency	5751	6.13
Recent intake	2066	2.20
LTC placement	1502	1.60
Client discharge & clinic nursing & recent intake	1404	1.50
LTC placement & recent intake	1338	1.43
LHIN & care coordinator	1150	1.23
Hospital discharge & recent intake	806	0.86
Clinic nursing	402	0.43
Hospital discharge	394	0.42
Client discharge & clinic nursing	222	0.24
Clinic nursing & recent intake	177	0.19
Total	93,774	100.00

Note: All clients and caregivers responded to questions about their LHIN and care coordinator, irrespective of the combination of questions that they were administered.
Abbreviations: LHIN=Local Health Integration Network; LTC=long-term care.

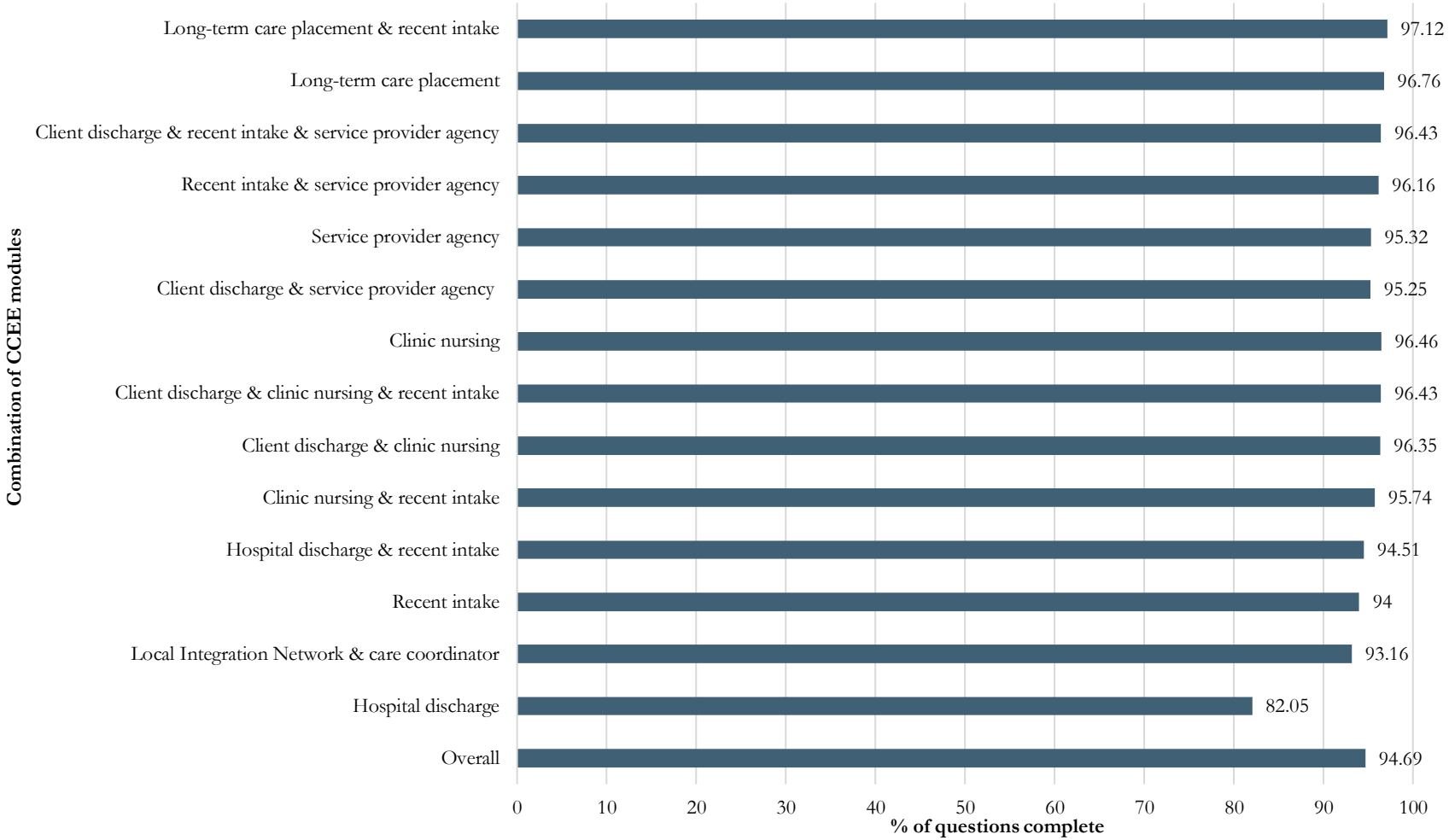

Figure 8. Average rate of completion of the CCEE

PERFORMANCE OF THE CCEE

Top and Bottom-Box Responses

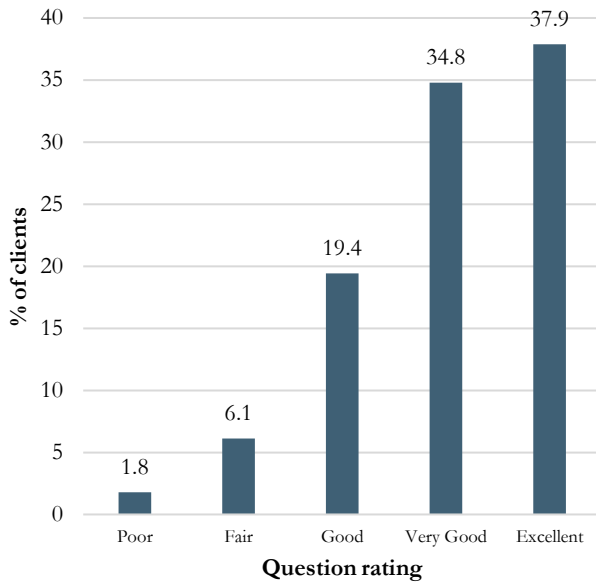

Figure 9. Overall quality of services organized and delivered by the LHIN and providers

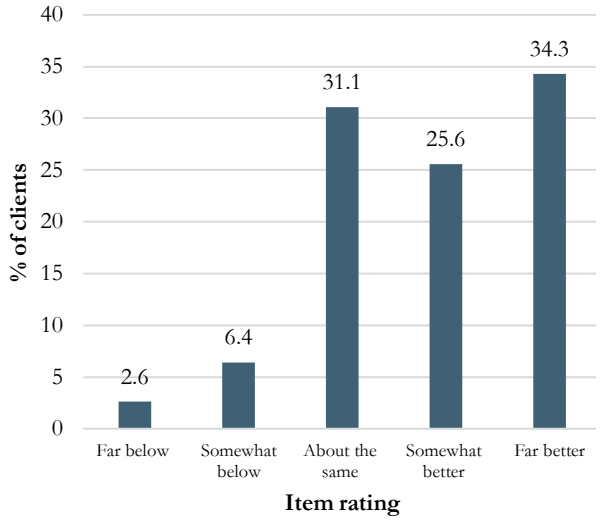

Figure 10. Comparison between overall quality of services organized and delivered by the LHIN and providers relative to expectations

The following sections highlight the distribution of responses to questions on the CCEE. First, the percentage of clients and caregivers who responded top- and bottom-box is addressed. Most clients and caregivers selected the most positive question option (e.g., "always", "definitely yes", "strongly agree", and "yes") in each of the 14 LHINs, with 70% of individuals in the sample responding top-box on average. This was consistent across all three fiscal years. Although these may represent accurate ratings, it is possible that there are potential ceiling effects. Conversely, a very small percentage of individuals responded bottom-box across the majority of questions.

However, some questions were not rated as highly including those that probed about client and caregiver involvement in the development of the care plan, wherein 57% answered top-box (Appendix D). Questions on familiarity with care coordinator (61%), ease of contacting care coordinator (57%), and whether the CCAC helped link client to other community services (57%) were also not rated as highly for the sample overall. For individuals who received clinic-nursing services, 25% responded top-box to a question on continuity of care, which emphasized whether the same provider delivered their services. Furthermore, the percentage of clients that were previously discharged from hospital who responded top-box was low for questions on the provision of health information post-hospital discharge (47%), explanation of medications (45%), and follow-up visits post-discharge (38%). These figures suggest that questions with high top-box ratings are either achieving outstanding performance, or the response scale or question wording might benefit from revision.

While the responses were mostly very positive, the global ratings of the delivery and organization of services were not as heavily skewed[3]. Figure 9 illustrates that only 38% of clients thought that their care was "excellent" overall. This is consistent with ratings of the care coordinator and service provider, wherein only 42% and 50% selected "excellent", respectively (results not shown). The discrepancy between the global ratings and individual-question scores suggests that the existing CCEE survey may not be capturing some aspects of the H&CC experience that are important to clients and caregivers [11]. Indeed, only 34% of individuals considered the quality of services to be "far better" relative to their expectations (Figure 10). To explore this possibility, the relationship between the global ratings and the average score, which is another summary measure of the overall quality of care, was examined. Indeed, it was found that the summary measures had less than perfect positive correlation, thereby suggesting that the existing CCEE survey is missing questions that are relevant for the H&CC experience. Lastly, 78% of respondents would definitely recommend their service provider to others. It is possible that this is because Ontarians are limited by their home care service options, as only private services are available beyond those that are publicly funded.

Patterns of Responses Across Demographic Groups

The following presents the findings from the demographic and equity analyses. These descriptive analyses provided insight into whether there were differences in the performance of the CCEE across various client groupings. The responses to questions were compared between clients that varied in age, sex, ethnicity, geographical location, need for healthcare, and the risk of institutionalization[4]. Furthermore, the differences in responses to the survey between clients and caregivers were also examined.

Age

There was minor variation in the responses across age groups. Of interest, caregivers who replied on behalf of children rated questions more positively relative to older clients. For example, 65% of caregivers strongly agreed that they were involved in developing the care plan that met the needs and preferences of the child under their care compared to 56% of older individuals. Sixty-four percent of caregivers thought that the LHIN helped link them to other community services when they needed additional support (results not shown). Caregivers (76% strongly agreed) were also much more likely to identify their care coordinator who is responsible for coordinating the necessary services required by the client. Conversely, the oldest old clients (≥85 years) experienced difficulties with access to service providers. Sixty-one percent and 55% of older individuals thought that service providers always arranged visits at a convenient time and kept their client informed about visits, respectively. Variation was not present for the other questions.

Sex

No differences in ratings were found between the sexes. Males and females rated their experience of home care highly positively overall.

Ethnicity

A notable trend that emerged was that Ontarians of East Asian background tended to rate questions more negatively compared to other ethnic groups. For example, only 43%, 39%, and 35% of Chinese, Japanese, and Korean clients strongly agreed that they were involved in the development of their care plan, respectively. Only 40% of Koreans thought that H&CC services started as soon as they needed it relative to 70% of among non-Koreans. All other ethnic groups rated their experience of home care positively overall.

Residence Location

No differences in ratings were found for clients and caregivers living in either rural or urban locations.

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[3] Global ratings refer to questions 4, 5, 24, 38, and 39 on the CCEE.

[4] Data on client demographics were obtained from the Home Care Database maintained at Health Shared Services Ontario (HSSO).

CCM Classification

Adult, short-stay clients rated several questions more positively compared to independent and long-stay home care clients. This included questions relating to the timing of H&CC service provision, appropriateness of the care plan, ease of contacting the care coordinator, the care coordinator assisting the client with obtaining necessary services, and the overall quality of the services provided by the care coordinator. For example, 75% of these clients strongly agreed that the care coordinator helped them to obtain needed services. Short-stay clients were also satisfied with their service provider as 85% strongly agreed that their provider understood their needs, provided the agreed upon services, and made good use of their time while providing care.

Risk of Placement in a LTC Home

No differences in ratings were found between clients belonging to each of the LTC home risk stratifications. This is notable because clients at high levels of risk would have conditions and care needs that are far more complex to coordinate and deliver as compared to those at the lower risk levels.

Comparison of Client and Caregiver Responses

Among respondents, there were n=16,649 caregivers that answered on behalf of a client receiving H&CC services. Most of the proxy responses were for older individuals relative to the remainder of the sample, with 60% of them above the age of 75 years. This was consistent across each of the LHINs. In addition, they also had poorer health status; 60% were classified as either medically complex or chronic and had high risk of being admitted into a LTC home. Therefore, it is appropriate that a caregiver responded to the survey for them.

Proxy responses were generally similar to those from clients. However, some questions were rated more positively. For example, caregivers of individuals that recently began receiving services expressed that a provider had contacted them about the client's care needs and they felt involved in developing their care plan more often. This was observed in each of the LHINs and across all fiscal years. Consistent with this, the caregiver was more likely to recognize who the care coordinator was. Other questions that received higher positive ratings included those which focused on the LHIN linking clients to community service supports and safety concerns both within the home and as discussed by the care coordinator.

Response Variation Between LHINs and Between Providers Within Networks

Variations in responses to questions were then examined to identify areas for quality improvement. Minimal variation was observed between LHINs for each question, which was consistent across the fiscal years 2014-2016[5]. Similarly, each question was compared on the amount of variation between providers within LHINs and minimal variation was found. This was consistent across fiscal years for most questions[6]. Yet, Q26: "Received services from agency", Q36: "Always had same service workers", Q37: "Care from different service workers caused problems", and Q41: "CCAC helped link to other community services" exhibited the most variation between providers within LHIN.

Assessment of Potentially Redundant Questions

A correlational analysis was performed to determine whether survey questions are repeated unnecessarily. Removing questions that collect similar information may reduce the burden of response on

[5]Variation was calculated with the coefficient of variation. The coefficient of variation was determined as the ratio of the standard deviation of the mean of the survey responses for each LHIN (and provider within LHIN) to the grand mean of those responses in each fiscal year (2014-2016).

[6]Bayshore Healthcare Ltd., CBI, CarePartners, Carefor, Health & Community Services, CommuniCare Therapy Inc., Closing the Gap Healthcare Group Inc., ParaMed Home Health Care, Revera Health Services Inc., S.R.T. Med-Staff, Saint Elizabeth Health Care, Spectrum Health Care, VHA Home HealthCare, Victorian Order of Nurses, We Care Health Services Inc. were the only service providers considered in the calculation of the coefficient of variation due to small sample sizes.

survey recipients and increase the likelihood of survey completion [12]. As Table 3 indicates, the relationship between measures that are used for contract management, public reporting, quality improvement plans, Ministry-LHIN Accountability Agreements (MLAA) and the remaining questions are of moderate-strength, given correlational coefficients that range between 0.40 and 0.70 in absolute value [11]. Of note, Q18c and Q41 were identical questions asking about the role of the care coordinator in linking to other community-based services either while concurrently receiving publically funded home care or after discharge from home care, respectively. Additional inspection of the content of the other questions did not suggest that there were redundant questions that may be omitted to decrease the length of the survey.

Table 3. Top three questions correlated with measures used for contract management, public reporting, quality improvement, and the MLAA

Measures	Questions with the highest correlation coefficients		
Contract management			
Q32b Service worker visits arranged at convenient time	**Q34** 0.47**	**Q32c** 0.46**	**Q35** 0.43**
Q32c Service worker arrived on time	**Q34** 0.47**	**Q35** 0.39**	**Q28** 0.32**
Q34 Kept informed about when the service worker would arrive	**Q32c** 0.47**	**Q32b** 0.47**	**Q35** 0.47**
Q37 Care from different service workers caused problems	**Q39** -0.39**	**Q38** -0.37**	**Q27a** -0.35**
Public reporting			
Q11a Felt involved in developing care plan	**Q11b** 0.54**	**Q18b** 0.45**	**Q18a** 0.44**
Q28 Home health providers explained things understandably	**Q29** 0.59**	**Q27b** 0.44**	**Q27a** 0.43**
Quality Improvement Plans			
Q4 Overall quality of services	**Q05** 0.56**	**Q39** 0.56**	**Q24** 0.55**
Q24 Rate management/handling of case by care coordinator	**Q18b** 0.57**	**Q18a** 0.56**	**Q04** 0.55**
Q39 Rate services provided by agency	**Q04** 0.56**	**Q27b** 0.51**	**Q27a** 0.50**
Ministry-LHIN Accountability Agreement			
Q18c LHIN linked to other community services	**Q41** 0.62**	**Q40c** -0.38**	**Q18b** -0.38**
Q21 Care coordinator listened carefully	**Q20** 0.61**	**Q24** 0.51**	**Q18a** 0.51**
Q22 Treated with courtesy/respect by care coordinator	**Q21** 0.49**	**Q20** 0.40**	**Q18a** 0.37**
Q29 Home care providers from agency listened carefully	**Q28** 0.59**	**Q35** 0.51**	**Q30 & Q27a** 0.48**
Q30 Treated with courtesy/respect by home care providers from agency	**Q29** 0.48**	**Q28** 0.39**	**Q35** 0.38**
Q41 LHIN helped link to other community services (discharge only)	**Q18c** 0.62**	**Q40c** -0.42	**Q24** -0.40**

Note: Spearman's rank correlation was used to calculate correlation coefficients. Question 04, 24, and 39 are measures used for MLAA in addition to quality improvement plans; Q04: Overall quality of services, Q05: Overall quality of services relative to expectations, Q11b: Plan was right for my needs, Q18a: Care coordinator understood what was most important, Q18b: Care coordinator helped me get needed services, Q20: Care coordinator explained things understandably, Q21: Care coordinator listened carefully, Q22: Treated with courtesy/respect by care coordinator, Q24: Rate management/handling of case by care coordinator, Q27a: Service worker understood needs, Q27b: Service worker made best use of their time, Q28: Home health providers explained things understandably, Q29: Home care providers from agency listened carefully Q29 (clinic): Clinic providers listened carefully, Q30: Treated with courtesy/respect by home care providers from agency, Q32b: Service worker visits arranged at convenient time, Q32c: Service worker arrived on time, Q34: Kept informed about when the service worker would arrive, Q35: Service workers up-to-date regarding care/treatment at home, Q39: Rate services provided by agency, Q40c: Felt I could call care coordinator if help was needed again, Q41: CCAC helped link to other community services.
*p<0.001, **p<0.0001

Key Performance Indicators for H&CC

Consistent with the top- and bottom-box responses, most of the nine key performance indicators demonstrated excellent performance across each of the fiscal years as shown in Table 4.[7] Forty percent of clients and caregivers did not think that the quality of services from the LHIN, care coordinator, and provider agency was better than they expected. This re-emphasizes the fact that the existing CCEE survey may not be capturing some aspects of the H&CC experience that are important to clients and caregivers. Performance measures relating to continuity with service providers, overall satisfaction with providers, and feeling of involvement with the development of the care plan also showed highly positive responses overall. All of the indicators and performance measures analyzed by demographic group (age, sex, ethnicity, residence location, CMM classification, and MAPLe level) and proxy respondents had high scores that were similar to those described here (results not shown).

Table 4. KPIs for H&CC by fiscal year (2014 – 2016)

	Fiscal Year			
Key performance indicator for home care and community care/other performance measures	**2014 – 2015**	**2015 – 2016**	**2016 – 2017**	**Overall**
Overall satisfaction with LHIN, care coordinator, and service provider agency: % of respondents who are satisfied with their home care from both care coordinators and service providers (KPI 1)	92.16	91.93	91.98	92.02
Information provided to clients/caregivers and involvement of client in developing care plan: % of clients who were provided information about home and community care or were involved in care plan (KPI 2)	88.57	88.61	88.43	88.57
Patient-centred appointments: % of respondents who were satisfied with their appointment scheduling, provider punctuality, and diligence of provider in keeping them informed about arrival (KPI 3)	94.57	94.91	94.60	94.70
Understanding and addressing needs: % of respondents who thought their care needs were understood and addressed (KPI 4)	92.92	93.40	93.43	93.26
Building relationships and trust: % of respondents who were able to easily communicate with their care coordinator and provider and were treated with respect (KPI 5)	91.62	91.75	91.96	91.78
Linking to other services: % of respondents who thought their LHIN helped link them to other services in the community if they needed help (KPI 6)	82.23	82.11	82.99	82.48
Willingness to recommend LHIN: % of respondents who would recommend the LHIN to family or friends if they needed help (KPI 7)	96.85	96.43	96.33	96.52
Overall satisfaction relative to expectations: % of respondents who thought that the overall quality of services from the LHIN, care coordinator, and provider agency was better than expected (KPI 8)	60.44	59.76	59.56	59.90
Support for safety concerns: % of respondents who responded Agree to I was satisfied with the support received from the case manager/agency to address safety concerns at home‡ (KPI 9; 2014 - 2016)	75.76	75.58	-	75.67

[7] Refer to Appendix E for a description of the key performance indicators for home and community care by LHIN and fiscal year (2014-2016).

Support for safety concerns: % of respondents who responded Agree to I was satisfied with the support received from the care coordinator/agency to address safety concerns at home (KPI 9; 2016)*	-	-	92.00	92.00
% of respondents who were highly satisified with the overall quality of services from provider agency (non-KPI)	81.11	80.86	80.97	80.98
Respondent satisfaction with continuity of care (non-KPI)**	86.81	86.88	87.80	87.22
% of respondents who felt involved in developing their care plan (non-KPI)	84.13	84.12	83.85	84.02

Note: Empty cells indicate that the key performance indicator was not calculated for the fiscal year.
Abbreviations: SD=Standard deviation
*Calculated with Q23: Care coordinator addressed safety concerns (2016) and Q31: Agency addressed safety concerns (2016).
**Calculated with Q37: Care from different service workers caused problems

EXPLORATORY FACTOR ANALYSIS OF DOMAINS PRESENT IN THE CCEE

Identification of Domains

Exploratory factor analysis was performed to assess the psychometric properties of the survey, including determining the existence of any summative or overarching domains reflected by groups of questions[8]. Domains were initially obtained through the process of extraction, with the scree plot suggesting that two domains be retained. Then, the domains were rotated with the direct oblimin method to account for their inter-relatedness and to facilitate the interpretation of their meaning. Following rotation, only questions which demonstrated a strong relationship with one of the two domains were examined further (as indicated by the questions with factor loadings ≥0.40 in Table 5). Specifically, the content of those questions were evaluated to identify the presence of any common underlying themes. Therefore, two domains were revealed: "Delivery of home care services by provider agencies" and "interactions with the care coordinator from the LHIN". The domains consisted of ten and seven questions, respectively.

Construct Validity

Convergent Validity at the Question-Level

Construct validity, particularly item-convergent validity, was shown through the correlation between each individual question from the domains and scales that were created based on the constituent items[9]. A scale represents the sum of each client or caregiver's ratings for all of the questions from a domain. Correlations between the service provider questions and the service provider scale were all above the recommended cut-off of 0.30, with correlations ranging from 0.37-0.52 [13]. Each question about the care coordinator from the LHIN was also strongly correlated with the corresponding scale, with correlations ranging from 0.36-0.57.

Discriminant Validity at the Question-Level

Discriminant validity is essential for the design of questionnaires because it indicates that questions are not measuring what they were not intended to measure [10]. This type of validity was examined by comparing

[8]Exploratory factor analysis was performed with the core questions including Q6, Q13.a, Q13.b, and those that focused on the quality of care delivered by the care coordinator (Q17, Q18.a, Q18.b, Q20, Q21 Q22 Q23 (2016 only)) and service provider agencies (Q27.a, Q27.b, Q27.c, Q28, Q29, Q30, Q31 (2016 only), Q32.b, Q32.c, Q34, Q36, Q37). These questions had the largest number of responses.
[9]Summated rating scales were calculated as the sum of ratings across all questions on a domain and transformed to a score between 0 and 100: Transformed score=[(Observed scale score - lowest possible scale score)/range of scale scores]*100. Correlation coefficients for each question and scale scores that were corrected for overlap by removing the question from the calculation of the summated rating scale were calculated with Spearman's Rank Correlation.

the size of the correlations between the questions from the domains and their respective scales with that of their correlations with the other scale. All questions were more strongly correlated with their own respective scales (e.g., "Delivery of home care services by provider agencies") relative to the other scale which reflects a different theme (e.g., "Interactions with the care coordinator from the LHIN") regarding the H&CC experience.

Internal Consistency of Responses to Questions from Each Domain

Cronbach's alpha statistic, α, was used to determine the extent to which the ten and seven questions measure their respective domains. The responses to the questions that were retained had reliability coefficients of $\alpha=0.87$ and 0.86 for the "Delivery of home care services by provider agency" and "Interactions with the care coordinator" domains, respectively. These values exceeded the recommended cut-off value of $\alpha=0.70$, suggesting that the responses were reliable [14]. No items were identified which may have been removed to improve the internal consistency.

Descriptive Characteristics of Each Domain

Summated rating scales were calculated as the sum of ratings across all questions from each domain and transformed to a score between 0 and 100. Descriptive summary statistics of the scales are presented in Table 6. Both scales are negatively skewed and were centered above a 95% rating, indicating that the responses for the questions on the two domains were generally rated positively. This is consistent with the analysis of top-box responses reported previously.

Table 5. Estimates of the factor loadings and communality estimates from the exploratory factor analysis

Factor Pattern (rotated pattern matrix)		Factor Structure (structure matrix)		Communality estimates (h^2)	Question on the CCEE
Domain 1	Domain 2	Domain 1	Domain 2		
					Q27. I would now like to read you some statements about the quality of care you/ [client salutation, client surname] have received from the *[care coordinator title]* from *[service provider organization]*. If you/ [client salutation, client surname] had care from more than one *[care coordinator title]* please think about the quality of care overall. Please tell me whether you agree or disagree with each statement.
0.81	-0.068	0.77	0.30	0.61	a) The *[care coordinator title]* understands my [client salutation, client surname] needs.
0.82	-0.056	0.79	0.31	0.64	b) The *[care coordinator title]* made the best use of their time with me/ [client salutation, client surname].
0.78	-0.019	0.77	0.33	0.59	c) The *[care coordinator title]* provided the services that I/ [client salutation, client surname] agreed to as part of my/her/his care plan.
0.64	0.083	0.68	0.37	0.47	Q28. In the last 2 months of care, how often did home health care providers from the *[service provider agency]* explain things in a way that was easy to understand?
0.74	0.050	0.76	0.39	0.59	Q29. In the last 2 months of care, how often did home health care providers from this agency listen carefully to you/ [client salutation, client surname]?
0.64	0.0062	0.64	0.29	0.41	Q30. In the last 2 months of care, how often did home health care providers from this agency treat you/ [client salutation, client surname] with courtesy and respect?
0.63	0.096	0.67	0.38	0.46	Q31. Agency addressed safety concerns
0.60	0.034	0.61	0.30	0.38	Q32b Were visits from the *[service provider title]* arranged at a convenient time?
0.57	-0.0065	0.57	0.25	0.32	Q32c In the last two months of care, the *[service provider title]* arrived on time?
0.60	0.021	0.61	0.29	0.37	Q34. How often did this agency or the *[service provider title]* keep you informed about when the *[service provider title]* would arrive?
0.070	0.57	0.33	0.61	0.37	Q17. How easy or difficult, on average, has it been to contact your *[client's first name]* LHIN when you needed to?

					Q18. I would now like you to think about the times when you have seen or spoken to your/ *[client salutation, client surname]* care coordinator. Please tell me whether you agree or disagree with the following statements.
-0.021	0.79	0.33	0.78	0.61	a) The Care Coordinator understands what is/was most important to me/ *[client salutation, client surname]*
-0.010	0.79	0.35	0.78	0.62	b) The Care Coordinator helps me get the services I need/ The Care Coordinator helps [client salutation, client surname] get the services he/she needs.
-0.0063	0.70	0.31	0.70	0.49	Q20. How often did the Care Coordinator explain things in a way that was easy to understand?
-0.030	0.78	0.32	0.76	0.58	Q21. How often did the Care Coordinator listen carefully to you?
-0.064	0.66	0.23	0.63	0.40	Q22. How often did the Care Coordinator treat you with courtesy and respect?
0.082	0.67	0.38	0.71	0.51	Q23. Care coordinator address safety concerns.

Note: Domain 1 - Delivery of home care services by provider agency; Domain 2 - Interactions with the care coordinator.

Table 6. Descriptive statistics of the domains identified through exploratory factor analysis

Domain	Number of questions	Mean (SD)	Median (IQR)	Range	Skewness	Kurtosis
"Delivery of home care services by provider agencies"	10	90.80 (14.25)	96.66 (87.03 - 100)	0 - 100	-2.35	9.72
"Interactions with the care coordinator from the LHIN"	7	87.80 (17.58)	95.23 (82.14 - 100)	0 – 100	-2.14	8.13

Abbreviations: IQR=Interquartile range; LHIN=Local Health Integration Network; SD=Standard deviation

SUMMARY OF QUANTITATIVE ASSESSMENT

The items from the existing CCEE survey were rigorously assessed to determine whether there were insufficiencies in the data completion rates or in the information available from the reported data. With the exception of some questions in the post-acute module (primarily for medication-related questions), we found that the existing survey appears to be easy for repondents to complete and the vast majority of respondents complete the full survey. We found that respondents provide ratings in essentially two relevant domains. One reflects their experience with the provider agencies and direct care providers and the second reflects their experience with CCAC or LHIN representatives. Summative scales based on the constituent items had robust statistical properties and constituted reliable measures of each domain. Individual item ratings and summative scales on both aspects of care all received very positive ratings, potentially indicating ceiling effects of the existing measurement of patient experience.

OPEN-TEXT COMMENTS

A Rationale for Qualitative Assessment

The respondents to the surveys provided highly positive ratings for agency and CCAC/LHIN services respectively. There was an option for respondents to also provide qualitative or open-ended comments at the end of the survey. A very large number of respondents took advantage of this opportunity. We consider these qualitative comments an opportunity to explore aspects of client experience that were not captured with items in the existing survey.

Method

A total of 320 open ended comments were purposively selected from the CCEE survey for analysis. In order to ensure responses from a diverse range of individuals we chose examples that represented:

a) residence location (urban/rural);
b) preferred language (English, French, Other);
c) respondent type (client vs proxy);
d) race (white, black, Indigenous, south Asian, other); amd
e) client case mix (adult - chronic or independent or well, adult – Complex, adult - short stay, child).

These were agreed to in consultation with our steering committee for the CCEE redevelopment project. For each of these five criteria we randomly selected 20 comments from all respondents in each group (e.g., urban and rural respectively). Respondents selected for one group or criterion were then removed before repeating the selection process for each of the other characteristics. This method generated a total population of 320 responses with at least 20 responses for each of the desired sampling stratum. Because some individuals sampled for a specific purpose would have other characteristics, the analytical sample contains more than 20 respondents for each category (i.e., respondents selected for a respondent type were also either of rural or urban geography although they were not selected for that purpose).

Data analysis was undertaken in the combined sample of all comments regardless of the sampling stratification by which they were selected into the analytical sample. Qualitative description was used to generate general summaries, and identify key categories (common passages of text) from open-text comments from client respondents [15]. The purpose of this analysis was to describe the experiences, and quality of H&CC that was delivered at the time participants completed the CCEE survey. A descriptive approach to coding was ideal for this analysis, as generating new theory was not the intention of this analysis. The purpose of reviewing the open-text comments was to simply describe the experiences of respondents, and not draw inferences or interpretations [15]. Common categories were derived inductively from the data. Consensus of categories and sub-categories was reached between researchers (AG & KK). Qualitative data analysis software, NVIVO9 [16] was used to manage and code open-text data.

To determine whether the current CCEE survey items addressed the unmet needs and care experiences of home care clients and caregivers, survey items were mapped across the identified categories to determine amendments or new questions considering aspects of care experience that were not captured in the existing survey instrument.

Results

Demographic Variables of Open Text Sample

Within this sample of home care clients, participants in the survey were mostly female (60%), between the ages of 19 to 64 (29%), and 75 – 84 (26%), and spoke English as their preferred language (75%). Clients mostly identified as White for their race (62%), were classified as *Adult – Chronic* for their home care service types (51%), and resided within an urban location (78%). We do not assess the repreesntativeness of this sample because it is a purposive sample with intended representation of a minimum of 20 respondents across each category regardless of population representation.

Table 7. Demographics of open text sample

Variable		Total Open-Text Comments (n=320)
Sex	Male	128 (40%)
	Female	192 (60%)
Age Category	0-18	27 (8.4%)
	19 - 64	92 (29%)
	65 - 74	58 (18%)
	75 - 84	82 (26%)
Language	English	241 (75%)
	Non-English	79 (25%)
Race	White	198 (62%)
	South Asian	32 (10%)
	Indigenous	20 (6.3%)
	Other	47 (15%)
	Black	23 (7.2%)
Client Type	Adult - Chronic	164 (51%)
	Adult - Complex	57 (18%)
	Adult - Short Stay	72 (23%)
	Child	27 (8.4%)
Residency	Urban	250 (78%)
	Rural	70 (22%)

Identified Categories

Four core categories were identified in the analysis and presented in Figure 11 below: sufficiency of H&CC, staffing, system organization and communication (Figure 11). A more detailed description of subthemes within each category can be referred to in Appendix F.

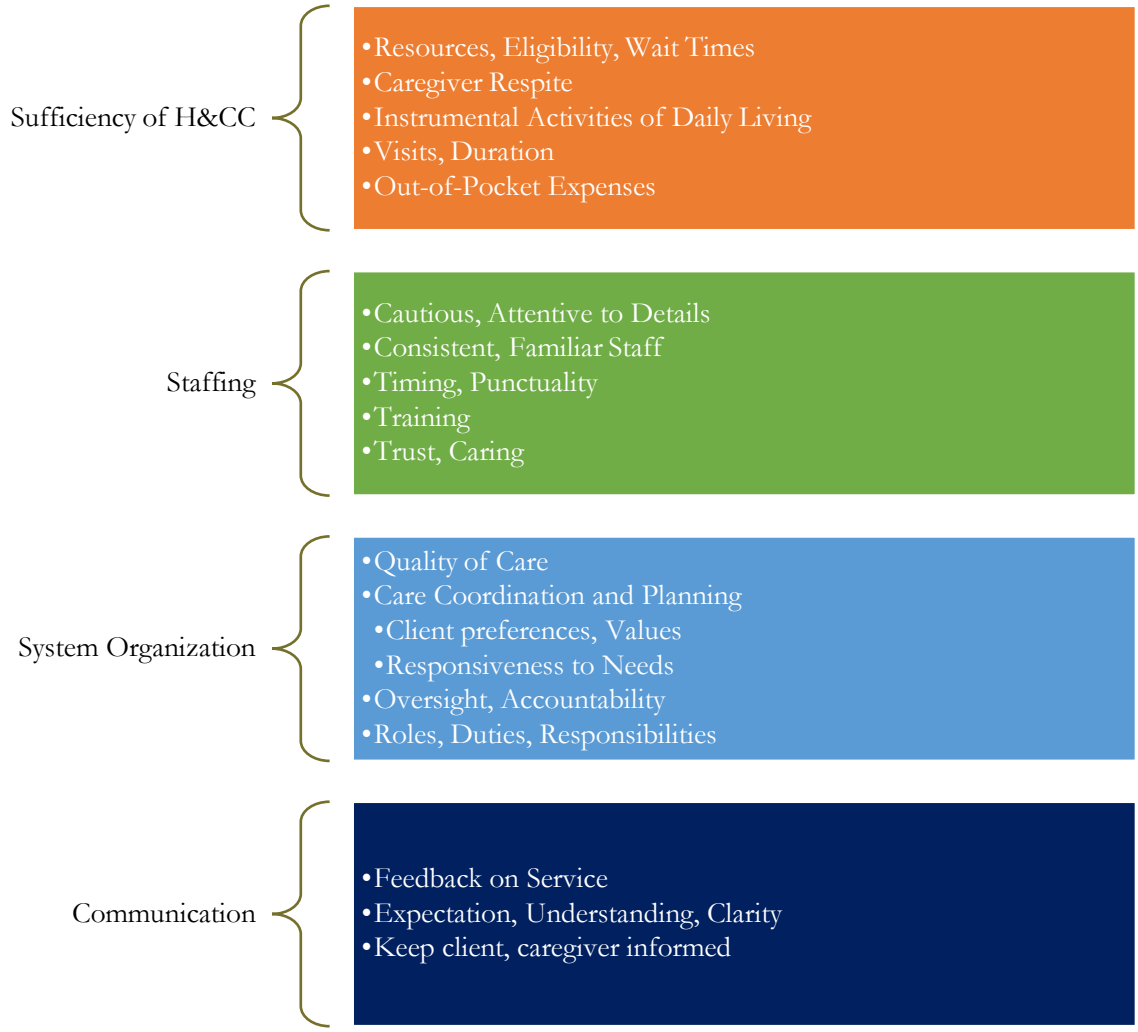

Figure 11. Overview of Identified Categories

Sufficiency of H&CC

Clients and caregivers wanted greater home care support, including more visits from physiotherapy, occupational therapy, nursing, house-keeping as well as respite care. More follow-up from the care coordinators and continued needs assessments to track changes in the client's needs was requested, to ensure eligibility for additional services. One client was struggling with how to find a motorized scooter as it was getting more difficult to be independent outside of the home,

> *"I'm trying to get a chair, and they can't seem to get me a power chair to help me get around outside. I have memory loss also, and I can't get help for that either."* (Comment 250, Client)

Limited *resources* (e.g., staff, visits and hours of care that can be provided) impacted *eligibility* and increased *wait times* for service initiation. Clients and caregivers complained that they had to spend *out-of-pocket* to "fill in" the gaps of care.

One caregiver noted the long wait time in getting an occupational therapist visit the home:

> "*There is some limitation. She is supposed to have an occupational therapist to see, but they said she has to wait six months or something like that. It's sometimes not very good for her because she needs the help. We have to wait six months. I don't understand why*." (Comment 204, Caregiver).

Additional supports included the need for greater respite for caregivers, as they often provided care around-the-clock:

> "*They could provide somebody else to come in. I have to dress him and undress him and make sure that he gets his medication. The nurse comes once a month to change the catheter and make sure that it works, and that's it. It would be nice if I could get some extra help once a week or so just to give me a break*." (Comment 98, Caregiver)

Staffing

Clients and caregivers preferred to have home care providers that were consistent and familiar with their limitations and preferences. They did not like having high turnover of personnel, especially during the holidays and weekends. Staff who were *attentive*, *cautious*, *trusting, caring, reliable,* and provided undivided attention to the client was highly valued. One caregiver preferred to have a consistent care coordinator to improve continuity of care:

> "*For the continuity of care, the case coordinator keeps changing very often. When I call in six months, the case coordinator will have changed. In the period of the last several years, we've had a new coordinator every year. Then it's sort of difficult to develop these relationships. I would suggest that if the case coordinator could stay the same, that would help. To the new person, we have to explain our needs again even though it's there written, but they don't understand until you meet with them and talk to them*." (Comment 172, Caregiver)

The training and expertise of staff was questioned during poor care experiences. One client preferred having home care workers that better stimulate home care clients:

> "*They should have better training for the workers so they fill up the time they are here. A lot of time, they don't have much to do. They don't have any ways to stimulate, exercise with them, or they're restricted in what they can do with the person they are taking care of. If they have better training, they can give better care and make better use of their time*." (Comment 191, Client).

The *timing* and *punctuality* of providers was a point of contention for clients and caregivers as home care workers were often late or unable to visit during scheduled times.

System Organization

Multiple people and organizations are involved in the management and delivery of home care. This was troublesome for clients and caregivers when accessing care and problematic for coming up with a solution for a specific unmet need. Disorganization with *care* planning and coordination between different levels (i.e., across the care coordinators, home care agencies and front line workers) of the home care system resulted in clients having "no show" providers, care at unplanned timesor no care at all.. Issues arose during transtitions of care. One client struggled with receiving services after hospital discharge,

> "*Better understanding of what my actual needs were. When I was discharged from the hospital I didn't have all the things that I needed so the OT had to call the case manager*." (Comment 223, Client)

Additionally, *oversight* and *accountability* of health care providers was required but it was unclear whether any processes were in place to ensure this. A frustrated client wished she had a way to express her discontent and to hold providers more accountable for the care they provide,

> "*Getting better checks and balances with home care providers. Basically, the people providing PSWs* [personal support workers] *[should be] held more accountability on the management of the PSW companies. PSW companies are not providing customer-centric care. They are providing profit-centric care.*" (Comment 154, Client).

Furthermore, it was important for provider roles, duties and responsibilities to be made clear to clients both for purposes of knowing who to contact as well as what to expect in their care.

> "*But I do need somebody to clean the floors, but that is not covered by the* [redacted] *services. I cannot always watch how the cleaning staff are doing their job. I sometimes ask them to do extra things, and they do it for me, but it is not part of their duties, and it is never guaranteed.*" (Comment 77, Client)

Communication

Clients and caregivers preferred to have home care providers introduce themselves, and communicate their role. More so, the schedule and timing of home care visits were often not communicated to the client/caregiver directly, including changes in staff attending their scheduled shift. One client had challenges with the daily schedule of home care providers,

> "*Go tell them to phone ahead of time. Give the client some notice if you're coming, the night before. I know the union doesn't allow it anymore, but tell the union to go back the way it was because we don't know if anybody is coming or going. We just don't know if we're getting home care. Sometimes, they don't phone or show up. Tell the care worker to at least have the courtesy to phone the people.*" (Comment 73, Client)

Information shared between the agency, LHIN and staff providing care was often inconsistent leading to confusion, and ambiguity regarding H&CC. One caregiver was unclear what services were available, as a central information source was not available.

> "*Just getting the news out there, getting what's available out there so that we know what there is, we're aging and possibly going to need more care and we don't think about phoning for help, we've been too independent all our lives*." (Comment 281, Caregiver)

Furthermore, clients preferred providers who could speak the client's preferred language when providing direct client support.

Comparison of Emerging Themes with CCEE Survey Items

Gaps and limitations of the current CCEE survey highlight possible amendments for the next iteration of the survey. Specific elements which contribute to a positive home care experience that aligns with patient/caregiver preferences are missed. The following bullet points illustrate additional aspects of client experience that can be incorporated into a new CCEE survey. These examples illustrate content areas that appear to be overlooked in the current survey.

- Some questions in the current CCEE ask clients if they feel the coordinator understands what is important to them; however knowing what is important doesn't necessary lead to the *delivery* of care that aligns with preferences.
- The care coordinator's *capacity* to take responsibility for addressing the needs, and being able to assess the client/caregiver's limitations was often doubted by clients. This is primarily due to the

fact that the care delivered usually does not match the unmet needs that clients/caregivers experience.

- Furthermore, with having many different providers involved, the care coordinator may not necessarily be the "go to" person who is most responsive to unmet needs, or take full responsibility of the client's care. Therefore, questions that ask about the coordinator in relation to organizing care may not resonate with clients or caregivers.
- No questions addressed the disorganization, and uncoordinated care between the different levels of H&CC (i.e., care planning and coordination from care coordinator, scheduling issues with home care agencies or community programs, PSW or nursing visits at home), and the inability to directly schedule/contact providers.
- Furthermore, having more probes, or follow-up questions of positive or negative experiences would further increase the understanding of what, exactly, would best support clients and caregivers. Simply asking, *are you satisfied with your care* and getting a 'yes' or 'no' response is not helpful.
- There was emphasis on questions which focus on *connecting,* and *linking* to services and resources from the care coordinator or LHIN. However, many providers are involved (e.g., agencies, community programs/groups, home care providers) with coordination and planning care. After the care coordinator *links* or *connects*, scheduling, communication, and follow-up from the individual providers are all a part of care coordination. Assessing the extent to which there was follow-up after being connected to services could be assessed.
- Questions which address the client's ability to report poor care experiences, especially without fear of retribution (e.g., PSW being upset, care coordinator being annoyed and therefore not providing/continuing care). Furthermore, ensuring the feedback is incorporated into provider training, and not simply reassigning staff to another client, is important, to ensure the delivery of client-centred care.
- Clients and caregivers were not always confident in a provider's experience and training, and felt uncomfortable with their care provision.

The CCEE survey items did address the need for consistent staffing, and the timing of the staff's arrival. However, further probing into other provider traits including the extent to which they are personable, likeable, dependable, reliable, patient and trustworthy would add value.

- Financial strain during home and community care could be explored, as out of pocket expenditures were an issue for some clients and caregivers. Furthermore, the provision of additional supports which are not currently covered by H&CC, such as home maintenance, house keeping, and meal preparation should be captured.
- Overall questions could be more specific, as the care coordination, listening, or explaining things carefully may not be enough, if the information provided is not *clear* about the roles, responsibilities of the home care providers, home care services, and what can be expected from the H&CC system.
- Providing information on *preparedness,* and ensuring the client/caregiver are prepared are different constructs, especially at different time periods, such as the beginning of initiating service, versus 3 or 6 months after services have been initiated.
- Direct and clear contact and communication with providers was highly valued, especially when providers were dispatched from an agency and timing/scheduling was an issue.
- Efficient communication pathways between different levels of home care (i.e., across the care coordinators, home care agencies and front line workers) was appreciated.
- Daily aspects of the care (on a daily or weekly basis), instead of general inquiry about the overall service, would provide more detailed information about unmet needs.
- Clients and caregivers had delayed notices in changes of the home care provider's schedule for visiting clients, and was highly disruptive to their daily function.

SUMMARY OF QUALITATIVE ANALYSIS

The existing CCEE survey has several strengths, but may benefit from improvements to its design to better elicit the views of Ontarians on their H&CC experience. Most notably, the discrepancy between respondents' ratings of the overall quality of services and care with other questions suggests that there are parts of this experience that are missing. To fully capture the client and caregiver home care experience the new CCEE survey can include questions that are more meaningful to clients and caregivers. For example, clients and caregivers access a variety of supports to manage their unmet needs, and often experience limitations when coordinating care and communicating across providers, agencies and community programs. Exploring the factors that shape a positive or negative experiences will shed light on what works well as well as what need to change to improve home care. This can be understood in light of the fact that the original intended purpose of the survey was to facilitate the management of provider contracts. Therefore, consideration should be given to integrating the feedback from clients and caregivers on what they value in H&CC in the development of the upcoming surveys.

CONCLUSION

This report was written to assess the validity, reliability and sensitivity of the existing CCEE survey measures. The report summarizes a quantitative and qualitative analysis of the existing CCEE survey using three years of data collected in Ontario between 2014 and 2016. Survey completion rates, response item distributions, factor and correlational analyses were all completed in addition to a qualitative analysis of a purposive sample of qualitative survey comments. The analyses were directed to answer a predetermined set of questions posed at the the outset of this project.

The current survey provides an assessment in two domains, namely for care providers and for CCAC/LHIN care coordinators. For these two domains, the survey appears to provide internally valid and consistent results. However the sensitivity of the existing tool appears to be sub-optimal with overall scores being highly similar across providers and regions and the very high scores suggests ceiling effects in the measurement. Several of the qualitative comments note areas where there are specific gaps in the existing survey. The summary recommendation of this report is that changes are necessary to the existing CCEE survey in order to better guage the experience of clients and caregivers who receive H&CC services. The findings here are indicative of the areas where clients and caregivers suggest improvements could be made.

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APPENDICES

APPENDIX A – LENGTH OF QUESTIONS AND RESPONSE FORMAT ON THE CCEE

Table 8. Number of words per question and response format on the client version of the CCEE

Client and Caregiver Experience Evaluation Question	Number of words	Response format	Number of response options	Do not know/ Do not remember/ Other option
Local Health Integration Networks questions				
Introduction	34	-	-	-
Q1. Received services from this Community Care Access Center	16	Multiple choice	3	No
Q2. Agency arranged services	18	Yes/no	2	No
Q3. Talk to the providers of home care services	24	Yes/no	2	No
Q4. Overall quality of services	23	Likert	5	Yes
Q5. Overall quality of services relative to expectations	15	Likert	5	Yes
Q6. Would recommend CCAC to family/friends	14	Likert	4	Yes
Introduction	57	-	-	-
Q13a Have access to written information in preferred language	13	Likert	5	Yes
Q13b CCAC could communicate in preferred language	22	Likert	5	Yes
Mean (SD)	22	-	4	-
Recent intake questions				
Introduction	41	-	-	-
Q7. Remember someone talking about what care was needed	15	Multiple choice	3	No
Q7b Remember someone talking re: care (prompt)	15	Multiple choice	3	No
Introduction	25	-	-	-
Q8.a Given needed information about CCAC services	13	Likert	5	Yes
Q8.b Home health care started as soon as needed	20	Likert	5	Yes
Q10. Told what care/services you would get	24	Yes/no	2	Yes
Introduction	18	-	-	-
Q11.a Felt involved in developing care plan	7	Likert	5	Yes
Q11.b Plan was right for my needs	7	Likert	5	Yes
Mean (SD)	15	-	4	-
Care coordinator questions				
Introduction	48	-	-	-
Q16. Know care coordinator	16	Multiple choice	3	Yes
Q17. Ease of contacting care coordinator	17	Likert	5	Yes
Introduction	32	-	-	-
Q18.a Care coordinator understood what was most important	10	Likert	5	Yes
Q18.b Care coordinator helped me get needed services	10	Likert	5	Yes
Q18.c CCAC linked to other community services	19	Multiple choice	3	Yes
Q20. Care coordinator explained things understandably	16	Likert	4	Yes
Q21. Care coordinator listened carefully	10	Likert	4	Yes
Q22. Treated with courtesy/respect by care coordinator	12	Likert	4	Yes
Q23. Care coordinator discusses safety issues	17	Likert	5	No
Q23. Care coordinator addressed safety concerns (2016 only)	-	Likert	5	-
Q24. Rate management/handling of case by care coordinator	16	Likert	5	Yes
Mean (SD)	16	-	4	-
Service provider agency questions				

Introduction	58	-	-	-
Q25. Received services from agency	13	Multiple choice	3	No
Q26. Received services from agency (prompt)	33	Multiple choice	3	No
Introduction	56	-	-	-
Q27.a Service worker understood needs	7	Likert	5	No
Q27.b Service worker made best use of their time	13	Likert	5	No
Q27.c Service worker provided agreed to services	17	Likert	5	No
Q28. Home health providers explained things understandably	29	Likert	4	Yes
Q29. Home health providers listened carefully	21	Likert	4	Yes
Q30. Treated with courtesy/respect by home health providers	23	Likert	4	Yes
Q31. Treated with courtesy/respect by home health providers	16	Likert	5	No
Q31. Agency addressed safety concerns (2016 only)	-	Likert	5	-
Q32.b Service worker visits arranged at convenient time	12	Likert	4	Yes
Q32.c Service worker arrived on time	14	Likert	4	Yes
Q34. Kept informed about when the service worker would arrive	21	Likert	4	Yes
Q35. Service workers up-to-date regarding care/treatment at home (2015, 2016)	-	Likert	4	-
Q36. Always had same service workers	25	Likert	3	Yes
Q37. Care from different service workers caused problems	19	Likert	4	Yes
Q38. Would recommend agency to family/friends	17	Likert	4	Yes
Q39. Rate services provided by agency	13	Likert	5	Yes
Mean (SD)	18	-	4	-
Client discharge questions				
Introduction	21	-	-	-
Q40.a Enough notice about when services would end	13	Likert	5	Yes
Q40.b Service workers prepared me for services to end	15	Likert	5	Yes
Q40.c Felt I could call care coordinator if help was needed again	17	Likert	5	Yes
Q41. CCAC helped link to other community services	27	Multiple choice	3	Yes
Mean (SD)	18	-	4	-
Long-term care placement questions				
Q42. Have been offered a place in a long-term care home	16	Yes/no	2	Yes
Q43. CCAC talked about other options for their care	23	Yes/no	2	Yes
Introduction	17	-	-	Yes
Q44.a CCAC explained things understandably	27	Yes/no	2	Yes
Q44.b CCAC understood what was most important to you	24	Yes/no	2	Yes
Q44.c CCAC answered all your questions	21	Yes/no	2	Yes
Q44.d CCAC helped find a home that matches needs	25	Yes/no	2	Yes
Q44.e CCAC provided enough information regarding preparing for move	32	Yes/no	2	Yes
Mean (SD)	23	-	2	-
Demographic questions				
Introduction	22	-	-	-
Q46. Rate overall mental or emotional health	12	Likert	5	Yes
Q47. Racial background	21	Multiple choice	15	Yes
Mean (SD)	18	-	10	-
Service alert questions				

Q48.a Expressed serious concerns	34	Multiple choice	5	-
Q48.b Want a phone call about concerns	28	Yes/no	2	-
Mean (SD)	31	-	3	-
Clinic nursing questions				
Q31.a Clinic was clean/organized	10	Yes/no	2	Yes
Q31.b Clinic nurse washed hands	20	Yes/no	2	Yes
Q28. Clinic providers explained things understandably	24	Likert	4	Yes
Q29. Clinic providers listened carefully	18	Likert	4	Yes
Q30. Clinic providers treated with courtesy/respect	20	Likert	4	Yes
Q32.b Clinic appointments arranged at a convenient time	13	Likert	4	Yes
Q32.c Clinic appointments started at scheduled time	20	Likert	4	Yes
Q34. Informed of next clinic appointment	21	Likert	4	Yes
Q36. Had same service worker at clinic	23	Likert	3	Yes
Mean (SD)	18	-	3	-
Hospital Discharge questions				
Q2.a Services started/re-started in last few weeks	26	Yes/no	2	No
Introduction	26	-	-	-
Q25.aa Help arranged after leaving hospital	13	Likert	5	Yes
Q25.ab Was given health info after leaving hospital	22	Likert	5	Yes
Q25.ac Medication was explained	9	Likert	5	Yes
Q25.b Amount of time between discharge and visit to provider	17	Multiple choice	4	No
Q25.c Better able to manage health conditions	16	Likert	5	No
Mean (SD)	18	-	4	-
Open comment				
Q45. Most important thing the LHIN can do to improve the quality of care	18	-	-	-

Abbreviations: CCAC=Community Care Access Centre, SD=Standard deviation

Note: Counts of the number of words per question are reflective of the actual, rather than paraphrased questions from the client version of the survey. Clients and caregivers did not have to respond to a particular section if they answered 'no' to the conditional branching questions (Q7, Q7b, Q16, Q25, Q26, Q42) or the question was not relevant (e.g., hospital discharge questions only applied to n=1,200 clients). Q48a was a question for the interviewer.

APPENDIX B – LANGUAGE OF ADMINISTRATION PREFERRED BY CLIENTS AND CAREGIVERS

Table 9. Languages preferred by clients and caregivers

Language	n	%
Arabic	242	0.26
Chinese - Cantonese	371	0.40
Chinese - Mandarin	120	0.13
Croatian	67	0.07
Dutch	102	0.11
English	60,869	64.91
French	2,085	2.22
French & English	328	0.35
German	198	0.21
Greek	143	0.15
Gujarati	97	0.10
Hindi	128	0.14
Hungarian	76	0.08
Italian	1,398	1.49
Polish	133	0.14
Portuguese	279	0.30
Punjabi	362	0.39
Russian	367	0.39
Spanish	156	0.17
Tagalog	83	0.09
Tamil	149	0.16
Ukrainian	87	0.09
Urdu	150	0.16
Other*	816	0.87
Missing	24,968	26.63
Total	93,774	100.00

*Other includes Achinese, Afar, Africaans, Afrihili, Akkadian, Albanian, Amharic, Lebanese, Aramaic, Armenian, Australian, Banda, Bangla, Bengali, Bosnian, Bulgarian, Burmese, Cambodian, Cebuano, Chaldean, Chichewa, other Chinese, Cree, Creoles and pidgins, Croatian, Czech, Danish, Dari, Dravidian (other), Dutch, Eastern Frisian, Efik, Egyptian, Elamite, Erzya, Estonian, Fanti, Faroese, Farsi, Filipino, Finnish, Flemish, Friulian, Ga, Gaelic, German, Germanic, Hakka, Hebrew, Hungarian, Iban, Igbo, Iloko, Indo-European, Indonesian, Iranian, Japanese, Kachin, Khmer, Kinyarwanda, Konkani, Korean, Kurdish, Lao, Latvian, Lithuanian, Low German, Macedonian, Malayalam, Maltese, Marathi, Micmac, Nauhatl, Neapolitan, Nepali, Non-verbal, Norwegian, Ojibwa, Persian, Pushto, Quechua, Raeto-Romance, Romanian, Salishan languages, Scots, Serbian, Sicilian, Sinhalese, Slavic, Slovak, Slovenian, Somali, Sundanese, Swahili, Swedish, Swiss German, Syriac, Telugu, Thai, Tibetan, Tigrinya, Turkish, Twi, Vietnamese, Wakashan, Yiddish, Yoruba

APPENDIX C – COMPLETION RATES OF INDIVIDUAL QUESTIONS

Table 10. CCEE question-level completion rates.

Client and Caregiver Experience Evaluation Question	n	%
Local Health Integration Networks questions		
Q1. Received services from this CCAC	93,771/93,774	99.99
Q2. Agency arranged services	4,335/4,335	100.00
Q3. Talk to the providers of home care services	14,349/14,349	100.00
Q4. Overall equality of services	92,784/93,774	98.94
Q5. Overall quality of services relative to expectations	88,286/93,774	94.14
Q6. Would recommend CCAC to family/friends	91,088/93,774	97.13
Q13a Have access to written information in preferred language	85,279/93,774	90.94
Q13b CCAC could communicate in preferred language	88,867/93,774	94.76
Recent intake questions		
Q7. Remember someone talking about what care was needed	47,187/47,187	100.00
Q7b Remember someone talking re: care (prompt)	5,881/5,881	100.00
Q8.a Given needed information about CCAC services	41,201/42,662	96.75
Q8.b Home health care started as soon as needed	41,295/42,662	96.79
Q10. Told what care/services you would get	42,648/42,662	99.96
Q11a Felt involved in developing care plan	40,596/42,662	95.15
Q11.b Plan was right for my needs	41,480/42,662	97.22
Care coordinator questions		
Q16. Know care coordinator	91,874/93,774	97.97
Q17. Ease of contacting care coordinator	60,036/66,735	89.96
Q18.a Care coordinator understood what was most important	64,489/66,744	96.62
Q18.b Care coordinator helped me get needed services	64,525/66,747	96.67
Q18.c CCAC linked to other community services	63,776/66,755	95.53
Q20. Care coordinator explained things understandably	63,820/66,775	95.57
Q21. Care coordinator listened carefully	63,976/66,742	95.85
Q22. Treated with courtesy/respect by care coordinator	65,398/66,742	97.98
Q23. Care coordinator discusses safety issues (2014, 2015)	41,500/41,501	99.99
Q23. Care coordinator addressed safety concerns (2016 only)	23,599/25,274	93.37
Q24. Rate management/handling of case by care coordinator	65,759/66,747	98.51
Service provider agency questions		
Q25. Received services from agency	89,732/90,934	98.67
Q26. Received services from agency (prompt)	4,520/4,520	100.00
Q27.a Service worker understood needs	84,614/86,582	96.39
Q27.b Service worker made best use of their time	84,508/86,582	97.60
Q27.c Service worker provided agreed to services (2015, 2016)	50,724/59,900	84.68
Q28. Home health providers explained things understandably	80,847/84,315	95.88
Q29. Home health providers listened carefully	81,755/84,315	96.96
Q30. Treated with courtesy/respect by home health providers	83,412/84,315	98.92
Q31. Told how to set up home to move around safely (2014, 2015)	50,852/54,431	93.42
Q31. Agency addressed safety concerns (2016 only)	28,260/29,884	94.56
Q32.b Service worker visits arranged at convenient time	82,888/84,315	98.30
Q32.c Service worker arrived on time	82,306/84,315	97.61
Q34. Kept informed about when the service worker would arrive	81,199/84,315	96.30
Q35. Service workers up-to-date regarding care/treatment at home	25,439/26,682	95.34
Q36. Always had same service workers	82,197/84,315	97.48
Q37. Care from different service workers caused problems	33,990/37,414	90.85
Q38. Would recommend agency to family/friends	84,807/86,582	97.95
Q39. Rate services provided by agency	85,820/86,582	99.12
Client discharge questions		
Q40.a Enough notice about when services would end	29,122/30,827	94.46
Q40.b Service workers prepared me for services to end	28,812/30,827	93.46
Q40.c Felt I could call care coordinator if help was needed again	29,299/30,827	95.04
Q41. CCAC helped link to other community services	29,795/30,827	96.65

Long-term care placement questions		
Q42. Have been offered a place in a long-term care home	2,840/2,840	100.00
Q43. CCAC talked about other options for their care	2,584/2,760	93.62
Q44.a CCAC explained things understandably	2,693/2,760	97.57
Q44.b CCAC understood what was most important to you	2,612/2,760	94.63
Q44.c CCAC answered all your questions	2,684/2,760	97.24
Q44.d CCAC helped find a home that matches needs	2,652/2,760	96.08
Q44.e CCAC provided enough information regarding preparing for move	2,649/2,760	95.97
Demographic questions		
Q46. Rate overall mental or emotional health	91,614/93,774	97.69
Q47. Racial background	91,305/93,774	97.36
Service alert questions		
Q48.a Expressed serious concerns	93,771/93,774	99.99
Q48.b Want a phone call about concerns	618/618	100.00
Clinic nursing questions		
Q31.a Clinic was clean/organized	2,171/2,205	98.45
Q31.b Clinic nurse washed hands	1,931/2,205	87.57
Q28. Clinic providers explained things understandably	2,147/2,205	97.36
Q29. Clinic providers listened carefully	2,169/2,205	98.36
Q30. Clinic providers treated with courtesy/respect	2,188/2,205	99.22
Q32.b Clinic appointments arranged at a convenient time	2,182/2,205	98.95
Q32.c Clinic appointments started at scheduled time	2,179/2,205	98.82
Q34. Informed of next clinic appointment	2,052/2,205	93.06
Q36. Had same service worker at clinic	2,142/2,205	97.14
Hospital Discharge questions		
Q2.a Services started/re-started in last few weeks	1,200/1,200	100.00
Q25.aa Help arranged after leaving hospital	1,132/1,132	100.00
Q25.ab Was given health info after leaving hospital	1,132/1,132	100.00
Q25.ac Medication was explained	407/1,132	35.95
Q25.b Amount of time between discharge and visit to provider	1,132/1,132	100.00
Q25.c Better able to manage health conditions	1,132/1,132	100.00

Abbreviations: CCAC=Community Care Access Centre

Note: Questions from the CCEE were paraphrased. Clients and caregivers did not have to respond to a particular section if they answered 'no' to the conditional branching questions (Q7, Q7b, Q16, Q25, Q26, Q42) or the question was not relevant (e.g., hospital discharge questions only applied to n=1,200 clients). Q23 (Care coordinator addressed safety concerns) and Q31 (Agency addressed safety concerns) were only asked on the 2016 version of the survey. Q23 (Care coordinator discussed safety issues), Q31 (Told how to set up home to move around safely), and Q35 (Service workers up-to-date regarding care/treatment at home) were only asked on the 2014 and 2015 versions of the survey.

APPENDIX D – TOP- AND BOTTOM-BOX RESPONSES BY LHIN

Table 11. Percentage of clients and caregivers who selected the most positive or negative response for each question by LHIN

	Local Health Integration Network														
	CE	**CENT**	**CHAM**	**CW**	**ESC**	**HNHB**	**MH**	**NE**	**NSM**	**NW**	**SE**	**SW**	**TC**	**WW**	**Overall**
	%	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**	**%**
Rate services															
Excellent	41.3	31.3	36.7	33.9	41.8	37.7	32.4	42.8	40.1	38.3	42.8	38.8	37	38.2	37.9
Poor	1.6	2.0	1.7	2.5	1.8	1.9	2.1	1.8	1.7	1.6	1.3	1.8	1.8	1.6	1.8
Overall quality of services															
Far better than I expected	37.2	29.3	33.9	33.8	37.8	34.8	29.3	39.8	33.7	33.9	37	33	34.6	32.8	34.3
Far below what I expected	2.2	3.0	2.6	3.4	2.4	2.6	2.8	2.5	2.9	2.2	2.2	2.2	2.6	2.3	2.6
Would recommend CCAC to family/friends															
Definitely yes	80.2	77.2	78.7	77.9	79.8	78.5	77.1	81.9	78.5	78	79.5	77.9	78.8	78	78.7
Definitely no	1.2	1.4	1.3	1.8	1.4	1.4	1.7	1.2	1.8	1.1	1.2	1.6	1.3	1.3	1.4
Remember someone talking about what care was needed															
Yes, someone from CCAC talked to me	83.9	83.4	84.9	81.1	84.6	85.7	83.7	86.2	85.8	81.3	84.4	86.6	81.8	87.6	84.5
Yes, someone talked to me, but not sure if they CCAC	3.3	3.1	3.5	3.0	3.0	2.8	3.1	2.8	2.6	4.0	3.3	2.8	3.1	2.6	3.0
No, no one talked to me	12.8	13.5	11.6	15.9	12.4	11.5	13.2	11.0	11.6	14.7	12.3	10.6	15.1	9.7	12.5
Remember someone talking re: care (prompt)															
Yes, someone from CCAC talked to me	18.6	20.7	20.0	16.1	22.6	19.2	16.7	19.5	17.5	17.2	19.6	16.9	16.2	23.0	18.8
Yes, someone talked to me, but not sure if they CCAC	4.3	3.3	3.5	3.3	5.1	4.5	5.3	7.3	4.6	4.2	3.6	3.8	3.9	3.2	4.3
No, no one talked to me	77.1	76.0	76.5	80.5	72.3	76.3	78.0	73.3	77.9	78.5	76.8	79.2	79.9	73.8	76.9
Given needed information about CCAC services															
Strongly agree	72.9	66.6	68	68.2	73.3	69.8	66	73.6	71.6	74.6	73.3	72.2	68.1	72.4	70.7
Strongly disagree	1.6	2.8	2.0	2.7	2.2	2.2	2.0	1.5	2.4	1.8	1.4	1.9	2.0	1.8	2.0

	CE	CENT	CHAM	CW	ESC	HNHB	MH	NE	NSM	NW	SE	SW	TC	WW	Overall
	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%
Home health care started as soon as needed															
Strongly agree	77.9	67	68.6	69.5	76.7	72.9	68.8	73.1	72.1	78.7	76.5	73.7	74.6	74.1	73.2
Strongly disagree	3.1	5.2	4.6	6.0	3.4	4.5	4.7	3.7	5.8	2.7	3.1	3.9	3.3	3.6	4.1
Told what care/services you would get															
Yes	89.2	88.6	89.5	86.7	88.3	86.9	88.9	90.4	88.4	89.7	89.1	87.8	87.9	88.6	88.5
No	6.8	7.2	7.4	9.0	7.3	8.2	7.7	5.7	7.5	6.3	6.2	7.1	7.9	6.9	7.3
I don't remember	4.0	4.2	3.1	4.3	4.4	4.9	3.5	3.9	4.2	4.0	4.7	5.1	4.2	4.5	4.2
Felt involved in developing care plan															
Strongly agree	56.6	55.7	54.7	54.6	58.1	55.9	53.2	64.1	57.2	57.1	59.9	57	53.8	57.4	56.7
Strongly disagree	4.2	4.6	4.0	5.2	4.5	4.6	4.8	3.4	4.6	4	3.5	3.7	5	3.9	4.3
Plan was right for my needs															
Strongly agree	74.7	63.3	66.8	68	74.6	69.6	65.2	74.1	70.2	75	74.7	70.8	68.7	71.1	70.5
Strongly disagree	2.3	4.1	3.2	4.8	3.1	3.8	3.7	2.7	3.5	2.3	2.8	2.9	3.1	3.1	3.3
Have access to written info in preferred language															
Strongly agree	75	64	75	70.2	76.8	74.4	65.7	76.8	77	75.4	78.5	77.6	67.9	76.4	73.4
Strongly disagree	2.8	7.3	2.5	4.5	2.2	2.8	6.4	2.0	2.6	2.1	1.7	1.9	5.7	1.7	3.4
CCAC could communicate in preferred language															
Strongly agree	84.2	72.7	83.3	77.3	84.4	83.9	75.3	84.7	85.9	83.8	88	85.7	78.1	85	82.2
Strongly disagree	1.4	4.8	1.8	3.5	1.6	1.8	4.5	1.3	1.6	1.3	0.7	0.9	3.4	1.2	2.2
Know care coordinator															
Yes, this is my care coordinator	60.0	64.4	64.0	59.9	52.2	59.8	60.1	67.0	57.7	58.8	69.3	57.3	61.0	55.8	60.5
No, I don't know my care coordinator at all	30.3	25.6	26.3	30.0	36.1	30.2	29.1	24.1	32.7	33.0	22.8	31.7	29.3	32.4	29.5
Ease of contacting care coordinator															
Very easy	58.2	51.8	55.2	53.1	62	56.6	51.5	63.6	56.8	62.9	62.6	58.8	54.1	55.9	56.9
Very difficult	2.1	2.9	2.5	3.2	2.0	2.7	3.1	2.0	3.0	1.7	2.0	2.1	2.7	3.1	2.5
Care coordinator understood what was most important															
Strongly agree	69.5	68.7	68.8	65.7	72.7	67.8	64.9	72.6	67.1	71.0	72.2	69.9	67.6	68.8	69.0

	CE	CENT	CHAM	CW	ESC	HNHB	MH	NE	NSM	NW	SE	SW	TC	WW	Overall
	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%
Strongly disagree	3.0	2.8	1.8	3.1	2.4	3.1	3.0	1.7	3.3	1.6	2.6	2.7	2.9	2.4	2.7
Care coordinator helped me get needed services															
Strongly agree	71.4	68.1	69.4	66.6	75.0	70.1	66.1	74.4	69	73.2	74.8	72.1	69.6	69.9	70.5
Strongly disagree	2.6	2.9	2.1	3.9	2.5	3.1	3.1	1.8	3.3	1.7	2.5	2.8	2.6	3.0	2.8
CCAC linked to other community services															
Yes	47.6	58.2	57.8	55.5	59.2	58.7	55.1	61.5	56.9	55.9	57.7	60.8	55.6	59.6	57.0
No	11.6	14.4	13.4	15.5	9.5	11.6	13.2	11.3	12.6	11.2	9.9	10.1	14.0	10.0	12.1
Care coordinator explained things understandably															
Always	70.2	67.4	69.6	67.1	72.6	69.1	65.6	75	70.1	73.4	71.9	71.6	68.7	70.7	69.9
Never	3.0	2.6	2.1	3.5	2.7	2.5	3.0	1.7	2.8	2.2	2.7	1.8	2.8	2.0	2.6
Care coordinator listened carefully															
Always	76	73.8	75.8	73.9	78.3	74.3	72.6	80.3	75.1	79.3	76.9	77.0	74.6	76.0	75.7
Never	2.2	1.8	1.9	2.6	2.5	2.6	2.6	1.5	2.6	2.2	2.4	2.3	2.2	1.9	2.3
Treated with courtesy/respect by care coordinator															
Always	90.8	89.4	91.4	88.7	92	90.4	89.3	93.3	90.7	92.3	91.9	91.5	90.1	91.6	90.8
Never	0.8	0.9	0.7	1.3	1.1	1.1	1.2	0.6	1.3	0.8	1.1	0.8	0.8	1.0	1.0
Care coordinator discusses safety issues															
Yes	66.9	72.6	69.4	72.4	71	72.8	69.8	73.4	73.8	73.6	67.3	73.3	67.8	72.8	71.1
No	20.7	16.9	18.7	16.4	17.3	16.9	19.3	15.2	16.5	16.5	20.2	15.5	20.7	16.5	17.8
Care coordinator addressed safety concerns															
Strongly agree	73.5	73	73	69.3	75.1	71.9	72	79.1	71.5	73.6	76.4	76	74.3	72.6	73.5
Strongly disagree	2.2	1.9	1.9	3.2	2.3	2.4	2.0	1.5	3.0	2.1	1.9	1.8	2.6	2.3	2.3
Rate management/handling of case by care coordinator															
Excellent	42.5	34.1	40.6	36.8	44.9	40.6	34.7	48.0	40.2	42.6	45.6	42.0	39.0	40.1	40.6
Poor	3.3	2.7	2.5	4.0	3.0	3.2	3.1	1.9	3.5	2.1	2.5	2.6	2.6	2.9	2.9
Received services from agency															
Yes	91.2	88.8	90.1	91	93.6	90.5	89	90.1	93.6	91.4	91.3	91.2	90	87.8	90.7

	CE	CENT	CHAM	CW	ESC	HNHB	MH	NE	NSM	NW	SE	SW	TC	WW	Overall
	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%
No	3.4	5.9	6.4	5.1	3.0	5.4	5.8	5.9	3.7	3.7	5.1	4.7	4.7	7.6	5.0
Received services from agency (prompt)															
Yes	20.5	24.5	19.9	21.8	21.6	23.2	26.6	21.1	21.5	24.8	19	22.3	26	19.4	22.3
No	70.9	69.2	74.5	71.3	67.6	70.3	66	72.9	73.7	70.1	75.2	71.8	66.4	74.9	71.1
Service worker understood needs															
Strongly agree	81.9	76.8	76.9	78.6	83.7	78.6	75.7	80.6	80.6	78.6	82.9	80.9	77.6	79.9	79.5
Strongly disagree	1.0	1.5	1.4	1.6	0.9	1.5	1.2	1.1	0.9	1.4	1.0	1.1	1.5	1.2	1.2
Service worker made best use of their time															
Strongly agree	80.9	75	77.1	77.1	82.8	78.2	74.8	80.3	79.8	78.4	82.5	80.9	76.9	78.7	78.8
Strongly disagree	1.4	1.9	1.8	1.8	1.3	1.8	1.5	1.1	1.4	1.4	1.1	1.4	1.9	1.4	1.5
Home health providers explained things understandably															
Always	75.6	70.3	73.4	71.3	77.5	72.1	69.6	77.1	74.9	74	76.5	76.3	69.6	75.4	73.7
Never	2.8	4.2	3.6	4.0	3.0	3.9	4.6	2.9	3.6	4.4	2.9	3.0	4.3	3.1	3.6
Home health providers listened carefully															
Always	80.8	75.6	77.9	78	82.6	77.1	74	82.7	80.5	78.3	81.6	79.9	75.7	78.8	78.7
Never	1.0	2.4	1.7	2.4	1.3	1.8	2.7	1.7	1.6	1.9	1.5	1.6	2.2	1.5	1.8
Treated with courtesy/respect by Home health providers															
Always	91.6	90.2	91.5	89.6	93.1	90.8	89.6	93.3	92.6	90.5	93.8	92.3	89.4	91.8	91.4
Never	0.3	0.7	0.5	1.0	0.3	0.6	0.7	0.5	0.3	0.6	0.4	0.5	0.5	0.4	0.5
Told how to set up home to move around safely															
Yes	65.8	74.9	72.0	75.6	70.7	73.3	72.7	75.9	70.5	70.7	73.2	78.0	68.8	74.0	72.5
No	34.2	25.1	28.0	24.4	29.3	26.7	27.3	24.1	29.5	29.3	26.8	22.0	31.2	26.0	27.5
Agency addressed safety concerns															
Strongly agree	80.3	74.3	77.2	78	80.9	77.1	74.3	80.5	76.2	74.3	79.8	78.1	75.1	77.7	77.5
Strongly disagree	2.1	2.9	2.7	2.6	1.7	1.9	2.4	2.0	1.9	2.5	1.7	1.9	2.9	2.2	2.2
Service worker visits arranged at convenient time															
Always	76.5	75.1	78.2	78.4	78.2	75.9	74.4	80.2	75.7	75.6	81.2	79	74.9	78.8	77.2

	CE	CENT	CHAM	CW	ESC	HNHB	MH	NE	NSM	NW	SE	SW	TC	WW	Overall
	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%
Never	1.1	1.3	1.0	1.3	0.9	1.1	1.2	1.1	1.3	1.2	0.9	1.3	1.3	0.9	1.1
Service worker arrived on time															
Always	72.3	72.3	74.5	73	74	72.2	69.8	78.7	73.6	70	76	75.4	69.9	73.4	73.2
Never	0.8	1.1	1.1	1.3	0.8	1.2	1.4	1.0	0.6	1.4	0.7	0.7	1.1	1.0	1.0
Kept informed about when the service worker would arrive															
Always	73.7	71.4	74.5	73	76.4	72.6	70.2	78	74.4	74.3	78.1	76.5	69.5	76	74
Never	3.6	5.4	4.4	4.2	2.9	4.1	4.4	2.8	3.8	3.5	2.5	2.7	5.2	3.6	3.9
Service workers up-to-date regarding care/treatment at home															
Always	74.9	70.7	73.7	73	76.6	72	68.7	77.4	76	75.4	77.6	75.8	70.6	73.3	73.8
Never	1.8	4.0	2.5	3.0	1.8	3.2	3.9	1.9	2.7	2.7	1.8	2.4	3.7	2.9	2.8
Always had same service workers															
Always had the same worker	47.4	70.6	62.2	62.9	52.8	60.0	58.1	62.3	52.8	50.6	61.2	62.6	65.7	65.2	59.8
Often had different workers	17.0	6.7	13.5	10.1	13.9	13.6	13.2	11.0	15.8	19.6	11.6	11.2	7.6	11.1	12.4
Care from different service workers caused problems															
Always	5.1	7.8	5.8	7.1	5.5	6.9	6.4	7.5	6.4	7.3	4.5	6.0	7.1	5.8	6.3
Never	71.0	61.7	66.2	65.7	71.2	64.5	64.5	67.0	67.8	67.7	73.7	68.1	62.5	67.5	67.3
Would recommend to agency to family/friends															
Definitely yes	79.4	74.7	77.1	77.6	80.4	76.8	74	81.9	78.1	75.5	81.3	77.5	76.3	78.1	77.7
Definitely no	1.5	2.0	1.7	1.9	1.4	1.6	1.8	1.4	1.7	1.9	1.1	1.9	2.0	1.3	1.6
Rate services provided by agency															
Excellent	53.3	40.5	48.2	44.9	54.9	49.2	42.1	54.8	52	49.1	56	51.6	46.6	49.6	49.3
Poor	1.2	1.9	1.6	1.9	1.0	1.8	1.8	1.5	1.5	2.3	1.0	1.4	2.2	1.3	1.6
Enough notice about when services would end															
Strongly agree	77.9	67.1	72.3	74.1	76	72.6	71.3	78.2	77.5	80.3	77.8	74.5	72.7	75.2	75.0
Strongly disagree	2.4	4.0	3.4	3.6	4.8	4.2	3.9	3.1	3.7	2.6	2.6	3.2	4.7	3.1	3.5
Service workers prepared me for services to end															
Strongly agree	78.3	68.9	73.8	74.3	79.1	75	71.1	79.7	78.9	80.1	79.2	76.3	72.9	76.8	76.2

	CE	CENT	CHAM	CW	ESC	HNHB	MH	NE	NSM	NW	SE	SW	TC	WW	Overall
	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%
Strongly disagree	2.9	4.9	3.6	4.0	3.5	4.5	3.8	3.4	3.0	2.6	2.8	3.7	5.0	3.4	3.6
Felt I could call care coordinator if help was needed again															
Strongly agree	80.5	72.9	76.6	73.3	77.7	75.4	72	82.7	77.8	78.1	81.3	77.0	70.4	76.2	76.8
Strongly disagree	3.3	5.3	3.8	5.3	4.5	5.1	4.9	2.6	5.3	3.8	3.0	3.9	5.4	3.9	4.3
CCAC helped link to other community services															
Yes	22.4	29.3	26	29	26.3	28.6	29	28.5	22.2	24	26.2	32.6	22.2	27.5	26.6
No	15.1	22.1	17	20.4	15.9	20	19.4	14.8	15.5	16	14.1	16.7	19.2	15.8	17.1
Have been offered a place in a long-term care home															
Yes	96.6	97.2	97.2	100	97.0	97.5	97		98.5	95.3	98.8	98.8		95.1	97.2
No	3.4	2.8	2.8	0.0	3.0	2.5	3.0		1.5	4.7	1.2	1.2		4.9	2.8
CCAC talked about other options for their care															
Yes	62.2	65.7	59.0	76.6	61.8	69.7	64.6	72.4	68.6		65.5	63.0		66	65.5
No	37.8	34.3	41.0	23.4	38.2	30.3	35.4	27.6	31.4		34.5	37.0		34	34.5
CCAC explained things understandably															
Yes	92.6	94.1	93.1	93.8	95.6	89.1	91.0	96.2	89.7		92.9	94.2		90.0	92.7
No	7.4	5.9	6.9	6.2	4.4	10.9	9.0	3.8	10.3		7.1	5.8		10.0	7.3
CCAC understood what was most important to you															
Yes	85.8	90.1	91.8	88.9	93.5	86.3	85.5	93.4	89.5		92.3	91.3		87.0	89.7
No	14.2	9.9	8.2	11.1	6.5	13.7	14.5	6.6	10.5		7.7	8.7		13.0	10.3
CCAC answered all your questions															
Yes	88.9	93.1	94.9	92.2	92.5	90.1	93.2	95.4	90.3		93.3	92.2		88.8	92.1
No	11.1	6.9	5.1	7.8	7.5	9.9	6.8	4.6	9.7		6.7	7.8		11.2	7.9
CCAC helped find a home that matches needs															
Yes	84.8	82.7	86	86.4	87.6	81.6	77.5	90.9	87		87.7	85.1		83.6	85.1
No	15.2	17.3	14	13.6	12.4	18.4	22.5	9.1	13		12.3	14.9		16.4	14.9
CCAC provided enough information regarding preparing for move															
Yes	77.5	87.9	84.0	85.9	84.6	79.1	77.0	86.5	80.0		82.2	79.2		80.0	82.0

	CE	CENT	CHAM	CW	ESC	HNHB	MH	NE	NSM	NW	SE	SW	TC	WW	Overall
	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%
No	22.5	12.1	16.0	14.1	15.4	20.9	23.0	13.5	20.0		17.8	20.8		20.0	18.0
Rate overall mental or emotional health															
Excellent	26.7	18.1	19.9	24	24.5	22.5	22.6	22.3	22.2	27.1	23.4	24.1	22.8	23.6	22.9
Poor	7.3	12.3	10.2	9.5	7.4	7.8	9.8	8.7	9.0	5.3	7.2	6.7	8.7	7.6	8.5
Expressed serious concerns															
Yes	0.6	0.7	0.8	0.9	0.5	0.7	0.9	0.7	0.5	0.4	0.5	0.7	0.7	0.5	0.7
No	99.4	99.3	99.2	99.1	99.5	99.3	99.1	99.3	99.5	99.6	99.5	99.3	99.3	99.5	99.3
Want a phone call about concerns															
Yes	69.2	86.2	73.2	71.4	71.8	73.1	76.2	61.1	64.7	46.2	69.0	52.4	84.4	64.3	71.2
No	30.8	13.8	26.8	28.6	28.2	26.9	23.8	38.9	35.3	53.8	31.0	47.6	15.6	35.7	28.8
Clinic was clean/organized															
Yes	98.4			98.7	98.9	93.2	98.0		95.2		98.9		98.0		97.1
No	1.6			1.3	1.1	6.8	2.0		4.8		1.1		2.0		2.9
Clinic nurse washed hands															
Yes	98.2			95.7	96.6	95.1	97.5		96.8		97.5		98		96.9
No	1.8			4.3	3.4	4.9	2.5		3.2		2.5		2.0		3.1
Clinic providers explained things understandably															
Always	81.3			83.8	83.6	78	80.2		79.7		86.2		76.7		81.6
Never	0.8			1.4	1.4	2.7	0.4		3.2		0.7		1.0		1.4
Clinic providers listened carefully															
Always	83.1			88	86	82.9	82.4		83.9		88.2		82.9		84.6
Never	1.1			1.3	1.0	2.0	0.8		1.6		0.9		0.0		1.2
Clinic providers treated with courtesy/respect															
Always	91.6			97.3	94.2	91.2	92.7		94.2		97		94.3		93.6
Never	0.0			0.0	0.0	0.4	0.4		0.0		0.0		0.0		0.1
Clinic appointments arranged at convenient time															
Always	82.1			89.3	90.7	82.3	79.7		79.1		89.4		69.5		84

	CE	CENT	CHAM	CW	ESC	HNHB	MH	NE	NSM	NW	SE	SW	TC	WW	Overall
	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%
Never	1.6			0.0	0.0	1.3	0.4		0.5		0.6		2.9		0.9
Clinic appointments started at scheduled time															
Always	72.6			65.3	71.9	57.8	67.8		63		75.6		62.9		68
Never	1.4			2.7	1.7	3.1	1.2		1.6		0.4		1.0		1.6
Informed of next clinic appointment															
Always	85.2			94.5	91.7	76.2	80.8		84.3		92.3		64.1		84.6
Never	4.5			1.4	0.7	7.8	3.8		4.1		1.4		16.3		4.3
Had same service worker at clinic															
Always had the same worker	25.9			14.9	22.3	22.4	22.5		32.6		36.4		21.8		26.5
Often had different workers	31.4			33.8	42.6	37.4	32.8		25.4		20.9		35.6		31.8
Services started/re-started in last few weeks															
Yes	95.3				94.2		93.6		94.5						94.3
No	4.7				5.8		6.4		5.5						5.7
Help arranged after leaving hospital															
Strongly agree	71.1				67.0		63.6		68.9						67.3
Strongly disagree	4.3				5.1		7.9		6.3						6.0
Was given health info after leaving hospital															
Strongly agree	48.5				49.6		45.2		46.3						47.3
Strongly disagree	11.6				10.5		13.2		11.6						11.8
Medication was explained															
Strongly agree	44.5						41.0		50.0						43.2
Strongly disagree	14.5						14.0		8.8						13.8
Amount of time between discharge and visit to provider															
Within 1 week	39.5				37.0		35.1		41.6						37.8
Did not visit	20.9				23.6		21.4		18.4						21.3
Better able to manage health conditions															
Strongly agree	59.8				65.2		56.2		56.3						59.4

	CE	CENT	CHAM	CW	ESC	HNHB	MH	NE	NSM	NW	SE	SW	TC	WW	Overall
	%	%	%	%	%	%	%	%	%	%	%	%	%	%	%
Strongly disagree	4.0				4.7		6.6		6.3						5.4

Note: Questions from the CCEE were paraphrased. Empty cells indicate that no clients or caregivers from the respective Local Health Integration Network responded to the question. Q23 (Care coordinator addressed safety concerns) and Q31 (Agency addressed safety concerns) were only asked on the 2016 version of the survey. Q23 (Care coordinator discussed safety issues), Q31 (Told how to set up home to move around safely), and Q35 (Service workers up-to-date regarding care/treatment at home) were only asked on the 2014 and 2015 versions of the survey.

Abbreviations: CCAC=Community Care Access Centre; CE=Central East; CENT=Central; CHAM=Champlain; CW=Central West; ESC=Erie St. Clair; HNHB=Hamilton Niagra Haldimand Brant; MH=Mississauga Halton; NE=North East; NSM=North Simcoe Muskoka; NW=North West; SE=South East; SW=South West; TC=Toronto Central; WW=Waterloo Wellington.

APPENDIX E – KEY H&CC PERFORMANCE INDICATORS BY LHIN

Table 12. Range of scores on key performance indicators for H&CC between LHINs by fiscal year (2014 – 2016)

Key performance indicator for home care and community care/other performance measures	Fiscal Year 2014 – 2015	2015 – 2016	2016 – 2017	Overall
Key performance indicators				
Overall satisfaction with LHIN, care coordinator, and service provider agency: % of respondents who are satisfied with their home care from both care coordinators and service providers (KPI 1)	90.42- 93.72	89.89- 93.73	89.99- 94.25	89.75- 93.54
Information provided to clients/caregivers and involvement of client in developing care plan: % of clients who were provided information about home and community care or were involved in care plan (KPI 2)	86.35- 91.44	85.84- 92.17	86.40- 92.50	86.63- 91.75
Patient-centred appointments: % of respondents who were satisfied with their appointment scheduling, provider punctuality, and diligence of provider in keeping them informed about arrival (KPI 3)	93.54- 96.96	93.23- 96.94	92.18- 96.70	92.87- 96.81
Understanding and addressing needs: % of respondents who thought their care needs were understood and addressed (KPI 4)	91.73- 95.05	91.15- 95.54	91.82- 95.47	91.96- 94.73
Building relationships and trust: % of respondents who were able to easily communicate with their care coordinator and provider and were treated with respect (KPI 5)	89.94- 93.24	89.62- 93.45	89.71- 93.74	89.82- 93.10
Linking to other services: % of respondents who thought their LHIN helped link them to other services in the community if they needed help (KPI 6)	79.10- 86.02	78.33- 86.30	77.16- 87.69	78.15- 85.69
Willingness to recommend LHIN: % of respondents who would recommend the LHIN to family or friends if they needed help (KPI 7)	96.43- 97.37	95.29- 97.82	95.45- 97.00	95.63- 97.05
Overall satisfaction relative to expectations: % of respondents who thought that the overall quality of services from the LHIN, care coordinator, and provider agency was better than expected (KPI 8)	56.18- 63.60	54.16- 63.84	52.95- 63.93	53.98- 63.34
Support for safety concerns: % of respondents who responded Agree to I was satisfied with the support received from the case manager/agency to address safety concerns at home‡ (KPI 9; 2014 - 2016)	70.91- 78.45	69.45- 81.29	-	70.16- 78.95
Support for safety concerns: % of respondents who responded Agree to I was satisfied with the support received from the care coordinator/agency to address safety concerns at home (KPI 9; 2016)*	-	-	90.70- 93.75	90.70- 93.75

Other performance measures				
% of respondents who were highly satisified with the overall quality of services from provider agency (non-KPI)	76.61-85.42	75.43-85.31	76.02-88.16	74.69-86.32
Respondent satisfaction with continuity of care (non-KPI)**	85.11-89.40	84.54-89.27	84.78-90.90	84.88-89.89
% of respondents who felt involved in developing their care plan (non-KPI)	80.54-87.53	79.12-90.95	81.19-89.66	81.27-89.26

APPENDIX F – DESCRIPTIONS OF SUB-CATEGORIES

Table 13. Subthemes of Emerging Categories

Sufficiency of H&CC		
Caregiver Respite	Additional support is required for informal caregivers to conduct their usual activities, as well as get a break from caregiving duties. At times, caregivers were responsible to the client's bedside care, and would have appreciated more support for such tasks (e.g., wound care, physiotherapy, exercises)	"They could provide somebody else to come in. I have to dress him and undress him and make sure that he gets his medication. The nurse comes once a month to change the catheter and make sure that it works, and that's it. It would be nice if I could get some extra help once a week or so just to give me a break." (Comment 98, Caregiver)
Resources, Eligibility, Wait times	Home care had limited capacity partly due to shortages and high turnover of staffing (high , PSW schedule changes, limited funding from the government to provide additional hours/visits of support, and lack of supplies and equipment provided for recovery, safety and independence at home. Eligibility for additional care (such as more physiotherapy) was an issue, as clients would have preferred greater support than allowed. Wait times were long, for the initiation of home care service, following hospital discharge, as well as placement into an alternate care setting (LTC, private nursing facility) while getting home care.	"There is some limitation. She is supposed to have an occupational therapist to see, but they said she has to wait six months or something like that. It's sometimes not very good for her because she needs the help. We have to wait six months. I don't understand why." (Comment 204, Caregiver) "They need to have more resources, like suture kits. They don't have the proper equipment anymore. I had to go and buy some myself." (Comment 246, Client) "In the beginning we were sent home with very little nursing and now I have asked for more. If someone would have told us we could have asked for more nursing sooner we could have asked for more nursing sooner and prevented certain issues. I was being treated as if I had one kid when I had twins and that was unfair." (Comment 302, Caregiver)
Instrumental Activities of Daily Living	Care coordinators noted that certain services were not available by the LHIN including home maintenance, house keeping, and services which facilitated the client and/or caregiver's safety and independence.	"Maybe have a little more availability for workers, like if I need grass cutting, snow shoveling or maintenance men, something like that." (Comment 30, Client) "Still need home care worker for light housework, she doesn't come anymore. It's been 2 yrs." (Comment 78, Client)
Visits, Duration	Increased time, hours, and visits was expressed and often requested by clients, who were then denied.	"They're only here for a couple of hours, and they have to quickly go through the help, check. It goes through so fast, I have to go, I have to go. I don't like the hurrying bit. I don't like that at all." (Comment 40, Client)
Out-of-Pocket Expenses	Additional care which was not financially covered by H&CC, which clients and caregivers paid for, included additional physiotherapy, home care supplies and equipment, home mobility aids, foot care, and if home was no longer a suitable place of care, a private nursing facility.	"I know the XXXXXXXXXXXXXXXXXX has a great move to provide care in homes for elderly to keep them in their homes longer, but in many cases, that's just passing costs onto the patient. For example, surgical equipment, some of it's partially paid and some of it is covered through (ADP), but certainly not all of it. A stair lift in my house would cost about $6,0000 to keep me in my home. A convalescent care facility in our XXXX area didn't have any vacancies, so I paid $3,000 to go to a private facility." (Comment 58, Client)
Staffing		
Cautious, attentive to details	It was important for home care providers to be attentive and pay extra attention to client's needs and limitations when providing care. For example, poor care experiences were discussed, where a home care provider (such as a PSW) would be distracted with conversation, or their mobile device, instead of providing client care.	Being more attentive in regards to my husband's sugar level. He went through quite a bit of discomfort, and it was a little traumatizing to us. He ended up having to have five injections daily of insulin. It was just due to the steroid, but I believe if it would have been caught, then maybe we would not have had so much trauma or discomfort for months. (Comment 224, Client) She wouldn't do some of the things she was supposed to do, she always had her phone ringing I just didn't feel confident in her. (Comment 255, Client)

Consistent, familiar staff	Clients and caregivers would appreciate having fewer turnover of staff, specifically, PSWs. Weekend and holiday schedules were very troublesome, as these were the periods of highest staff turnover, and it was particularly distressing for the client/caregiver to review tasks and preferences. Similarly, having nursing staff who are familiar with the client's medical needs (i.e., specifically, wound care) was preferred.	"For the continuity of care, the case coordinator keeps changing very often. When I call in six months, the case coordinator will have changed. In the period of the last several years, we've had a new coordinator every year. Then it's sort of difficult to develop these relationships. I would suggest that if the case coordinator could stay the same, that would help. To the new person, we have to explain our needs again even though it's there written, but they don't understand until you meet with them and talk to them." (Comment 172, Caregiver) "Continuity of care is most important, two or three carers is fine, but when it is five or six, that is difficult." (Comment 215, Client)
Timing, punctuality	Home care visits are usually scheduled for a specific time, as per the client's care plan. It's important to clients/caregivers for providers to respect these preferences. Furthermore, informing the client of changes in timing and schedule, was greatly appreciated, but rarely occurred.	"Have a company that provides personal care on time and at a good time and on time. I'm supposed to be seen first thing in the morning, and I'm never seen first thing in the morning." (Comment 19, Client) "I just finally said, I am sorry, if you cannot do like I would like. I have doctor's appointments. I am not sitting here waiting for you to call me or come. If you cannot do that, than I can put the dressing on myself". (Comment 57, Client)
Training	It was important o have staff who were skilled and competent to address the client's needs and preferences, particularly when managing complex symptoms and limitations, such speech and language issues, and/or dementia behaviours.	"The biggest difficulty with my father-in-law was the communication, his ability to communicate, so have strategies for people who have communication disorders, improved strategies of communication related to speech and language." (Comment 148, Client) "They should have better training for the workers so they fill up the time they are here. A lot of time, they don't have much to do. They don't have any ways to stimulate, exercise with them, or they're restricted in what they can do with the person they are taking care of. If they have better training, they can give better care and make better use of their time." (Comment 191, Client)
Trusting, Caring	Staff who provide direct client care, should have the following characteristics: be dependable, reliable, patient, trustworthy, and caring. Furthermore, the communication and 'people' skills of care coordinators was an issue, as they weren't personable when discussing sensitive issues. For example, sensitive conversations included LTC placement and planning, or ineligibility for a highly anticipated service. When delivering sensitive information, or coordinating care, speaking in a polite, patient way, was preferred.	"My point is if I can't trust them behind a closed door, then I can't trust your whole company. It's a shame because it's the people who come in on the weekend." (Comment 189, Client) "Their intake workers from XXXX, they need to be a little bit more personable. "31 "Keep sending this worker, and if she has to be replaced, have her be replaced with someone that is dependable and reliable." (Comment 68, Client) "One of them is that she is still without a family physician that has been totally neglected even though we have spoken to them until we are blue in the face; provide the proper social worker and the case manager that is caring". (Comment 197, Caregiver)
System Organization		
Quality of Care	Positive and negative experiences of specific interactions with H&CC. Comments about overall experience with home care, when a shorter interaction had occurred.	They say they have done this, this, this, and I have proved to them that they haven't. In fact, I called XXXXXXXXXXX on one person and said, Look, I won't have this person back. I've only got one wife. This lady lies at what she does, and I can

		prove it, so I told her how I did it and how I proved it. She said, I won't send her back. I said, I don't want her fired. (Comment 189, Client). I would just have to say to continue with the good work. They're so diligent. They listen. They pay so much attention to my wife's questions. They are so patient with her in explanation. Just to keep up the good work. (Comment 192, Caregiver) They were quick to suggest they were not coming to my home to treat me and that I should go to the office. I thought they were really quick in doing that. (Comment 273, Client)
Care Coordination and Planning	Aspects of care planning included speaking to the care coordinator and mobilizing care, receiving referrals for services, delays in service initiation, ordering supplies and equipment, and managing communication between different providers. Care planning was specific to the larger picture of care coordination, and accessing the broader system of H&CC. Planning transitions of care, from hospital to home, and for some, home to LTC or a nursing home. Challenges persisted with care coordination and planning, as it was unclear which provider was responsible and/or responsive to needs, how to make decisions with respect to services and care, and unmet needs which result from uncoordinated care.	"XXXX has been asked to place Mrs. XXXXXXX in a nursing home for several years. They have not. In fact, this is a matter I intend to take up with the Premier of the Province, my MPP, etc., etc. Overall, this woman has been hospitalized week in and week out. Although she lives in a retirement residence, she has been taken to hospital several times a year because she collapses, falls down, and has severe dementia. The XXXX feels she is just fine. The XXXX has said several times she is just fine. However, she has to be hospitalized by ambulance, twice this week, several times in a year, etc., etc., but no, she doesn't need to be in a nursing home. She has been on a nursing list for two years now. XXXX will not tell us when she might be in a nursing home." (Comment 155, Client) "I could get it at home. I live in the middle of nowhere. When I get really bad, the services, it will be nice to have them come up here." (Comment 233, Client)
Client Preferences, Values	Clients and caregivers expressed specific elements of home care service delivery which they preferred for a positive care experience. Such attributes include, greater exercise and support with mobility, consistent staffing, and specific training on client's limitations.	"They don't understand that even though this is regarding my father, my mother is also a XXXX client. She has dementia. It makes it difficult when they don't realize the other person has health issues. They sometimes can be quite abrupt with her because of the dementia. It makes it difficult when they don't understand there are two people that require XXXX, and they are just not coordinated enough to understand that." (Comment 130, Client) "They could improve by taking part in what XXXXXXX does and taking an interest in the client. Because when XXXX comes and meets with us, they say that this is what happens, and it's like they are in XXXXXXX side, not the client's." (Comment 139, Client)
Responsiveness to Needs	When unmet needs persisted, the reactiveness of care coordinators and other service providers was essential. When providers actively listened to clients and were able to address needs, this was highly appreciated and valued. Accurate assessment of unmet needs and limitations was also essential for the development and executing of the care plan. With multiple providers involved in a client's circle of care, it was a challenge to have one provider take responsibility of unmet needs, and then ensure care was provided.	"Because when XXXX comes and meets with us, they say that this is what happens, and it's like they are in XXXXXXX side, not the client's." (Comment 139, Client) "If they had of done their work right properly I wouldn't have taken a heart attack. I have to wear these compression stockings. VON think they are only socks, but they are compression socks to stop blood clots, so they don't think they have a specific schedule, which puts my life in danger." (Comment 166, Client) "A better understanding of what my actual needs were. When I was discharged from the hospital I didn't have all the things that I needed so the OT had to call the case manager." (Comment 223, Client)

		"We had a great experience. The physiotherapist was fantastic. She needed immediate intense physiotherapy, and that needed a few conversations to be arranged. It wasn't an easy thing to obtain." (Comment 309, Caregiver)
Oversight, Accountability	Clients and caregivers expressed the desire to have their home care providers regularly reviewed on their performance and ability to deliver high quality care. Clients and caregivers felt that this feedback should be given back to providers to support training for client centered care instead of dismissing the provider and/or reassigning them to another client, without sharing their performance review.	"Getting better checks and balances with home care providers. Basically, the people providing PSWs held more accountability on the management of the PSW companies. PSW companies are not providing customer-centric care. They are providing profit-centric care. Can you make sure that in my comments that XXXXXXX is mentioned? It is just that I am concerned. As a family, we are very supportive of XXXX. Our problem right across the board is strictly with XXXXXXX. It is very difficult for me. In other words, I am happy with XXXX. I am happy with the physiotherapists, etcetera. We have huge issues with XXXXXXX, their management, and dispatch. It is very frustrating. I was hoping to have this count in a different way than apparently it is going to." (Comment 154, Client)
Roles, Duties, Responsibilities	Due to the current organization of the different levels of home care (i.e., across the care coordinators, home care agencies and front line workers), clients and caregivers were unsure of which home care providers was responsible for a specific task or need. As communication and care coordination was at times difficult, it would further add to the ambiguity on specific roles of providers. Furthermore, at times, one specific provider who was a "champion of care," would fulfill the role of many providers and go out of their way to ensure needs were met. Additionally, when providers would not complete their responsibilities to the client's care and comfort, informal caregivers would "fill in" and complete tasks which they weren't always comfortable completing, such as maintaining exercise and physiotherapy, insulin management, and wound care.	"I was wanting a nurse to come for his dressings, but now it's been put back on me, I'm not completely able to do everything." (Comment 275, Client) "Don't think it is up to the coordinator to decide how often a bedridden person should get bathed or cleaned. Someone who is in bed needs more cleaning than someone that can walk around and do their own washing. That rule needs to be changed." (Comment 187, Caregiver) "But I do need somebody to clean the floors, but that is not covered by the XXXXXXXXXXXXXX services. I cannot always watch how the cleaning staff are doing their job. I sometimes ask them to do extra things, and they do it for me, but it is not part of their duties, and it is never guaranteed." (Comment 77, Client)
Communication		
Feedback on Service	Providing direct feedback on the care delivered, to management and organizational leaders was important for clients. Furthermore, having this feedback incorporated into the training and preparedness of providers was of added value, opposed to dismissing providers from their assigned client.	I made many complaints, and I do not think it ever went anywhere because they continued. I just finally said, I am sorry, if you cannot do like I would like. I have doctor's appointments. I am not sitting here waiting for you to call me or come. If you cannot do that, than I can put the dressing on myself. That was a mistake because it just escalated the problem. (Comment 57, Client)
Expectations, Understanding, Clarity	Clients and caregivers had varying expectations of H&CC, as some believed care would be unlimited or someone would be readily available for follow-up and support. Care coordinators also did not fully comprehend the client's context when allocating care and support, leading to an assessment of care provision which did not match the client's needs. Wait times for home care provision post-hospital discharge, and placement into LTC, were long and not made apparent to clients. Such misleading information and poor expectation management lead to increased ambiguity of the capacity H&CC can provide. Rules of eligibility for increased care (i.e., home making support, physiotherapy) were not clearly communicated to client, along with additional resources that were available.	"It would [be] nice to have the caregiver trained at hospital before sending the patient home. To focus more on what the caregiver and the person that needs the care are saying on what they actually need instead of what the XXXX think they might need." (Comment 21, Caregiver) "A better understanding of what my actual needs were. When I was discharged from the hospital I didn't have all the things that I needed so the OT had to call the case manager. My OT and my physiotherapist had to call to get things I knew I needed and my doctor knew I needed but the Case Manager didn't think I did". (Comment 223, Client) "The care itself we really used the nurse the dietician - no one explains the big picture as far as costs, equipment, the food, when does it stop, how does it all carry on - still wondering about that - the administrative stuff". (Comment 139, Caregiver)

		"Just getting the news out there, getting what's available out there so that we know what there is, we're aging and possibly going to need more care and we don't think about phoning for help, we've been too independent all our lives." (Comment 281, Caregiver)
Keeping client, caregiver informed	Timely communication to clients and caregivers, of provider schedules was a significant gap in service delivery. Clients often identified providers to be "no shows" to their shifts, as schedule changes were not shared between case managers, dispatch staff at the home care agency and the client. Rules of eligibility to specific home care providers, and placement to alternate settings of care (e.g., LTC, private nursing facility) were not clear and not communicated when discussing care planning and coordination.	"Go tell them to phone ahead of time. Give the client some notice if you're coming, the night before. I know the union doesn't allow it anymore, but tell the union to go back the way it was because we don't know if anybody is coming or going. We just don't know if we're getting home care. Sometimes, they don't phone or show up. Tell the care worker to at least have the courtesy to phone the people." (Comment 73, Client) "XXXXXX has contract with XXXX, but they don't have workers who can provide services; so I have to contact two agencies to contact, I would like to have only one agency to contact to provide us services." (Comment 44, Client) "There's miscommunication between the personal support workers with the care coordinators. I really think some of the girls are given information at the last minute. They are told to go somewhere with only an address. Don't know who they are even speaking with. We happened to be there for my mother when these girls came. It wasn't their fault. They didn't even know her name. They just knew a room number. There's something wrong between the linkage of who is doing what and when". (Comment 214, Client) "I was sent home with a catheter, and I didn't know how to operate the portable one to use the night bag. I wasn't really able to get hold of anybody that knew how to answer the question I was asking". (Comment 258, Client)
Communication		
Feedback on Service	Providing direct feedback on the care delivered, to management and organizational leaders was important for clients. Furthermore, having this feedback incorporated into the training and preparedness of providers was of added value, opposed to dismissing providers from their assigned client.	I made many complaints, and I do not think it ever went anywhere because they continued. I just finally said, I am sorry, if you cannot do like I would like. I have doctor's appointments. I am not sitting here waiting for you to call me or come. If you cannot do that, than I can put the dressing on myself. That was a mistake because it just escalated the problem. (Comment 57, Client)
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		"Just getting the news out there, getting what's available out there so that we know what there is, we're aging and possibly going to need more care and we don't think about phoning for help, we've been too independent all our lives." (Comment 281, Caregiver)
Keeping client, caregiver informed	Timely communication to clients and caregivers, of provider schedules was a significant gap in service delivery. Clients often identified providers to be "no shows" to their shifts, as schedule changes were not shared between case managers, dispatch staff at the home care agency and the client. Rules of eligibility to specific home care providers, and placement to alternate settings of care (e.g., LTC, private nursing facility) were not clear and not communicated when discussing care planning and coordination.	"Go tell them to phone ahead of time. Give the client some notice if you're coming, the night before. I know the union doesn't allow it anymore, but tell the union to go back the way it was because we don't know if anybody is coming or going. We just don't know if we're getting home care. Sometimes, they don't phone or show up. Tell the care worker to at least have the courtesy to phone the people." (Comment 73, Client) "XXXXXX has contract with XXXX, but they don't have workers who can provide services; so I have to contact two agencies to contact, I would like to have only one agency to contact to provide us services." (Comment 44, Client) "There's miscommunication between the personal support workers with the care coordinators. I really think some of the girls are given information at the last minute. They are told to go somewhere with only an address. Don't know who they are even speaking with. We happened to be there for my mother when these girls came. It wasn't their fault. They didn't even know her name. They just knew a room number. There's something wrong between the linkage of who is doing what and when". (Comment 214, Client) "I was sent home with a catheter, and I didn't know how to operate the portable one to use the night bag. I wasn't really able to get hold of anybody that knew how to answer the question I was asking". (Comment 258, Client)