

Integrated Funding Models Patient Experience Survey Final Report Authors Kevin Walker Ruth E Hall Walter P Wodchis

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HEALTH SYSTEM PERFORMANCE RESEARCH NETWORK (HSPRN)



This report presents results from the Integrated Funding Model Patient Experience Survey conducted by the IFM Central Evaluation Team from the Health System Performance Research Network (HSPRN) at the University of Toronto.

Survey methodology

The IFM Central Evaluation Team aims to complete 10 surveys per IFM program per month. Patients were randomly selected from the list of patients provided by each IFM program. Each IFM program obtained permission from patients prior to sharing the contact information with researchers at the University of Toronto. At the end of their bundled care period, patients were mailed an information letter and survey. A member of the IFM Central Evaluation team followed-up by telephone to answer any questions. If the patient preferred another mode, options to complete the survey electronically or by phone were available. If a randomly selected patient did not wish to participate in the survey or could not be contacted after at least 7 attempts over 60 days, they were replaced with another randomly selected patient from the IFM program.

The survey included questions on: 1) the patient's index hospitalization; 2) the transition back to their home and community after this hospitalization; and 3) the care received in their home and community during the episode. Questions were selected from a number of other surveys, including the Canadian Patient Experiences Survey, the Commonwealth Fund International Health Policy Survey of Older Adults and the Care Transitions Measure, among others.

How to interpret the results

This report presents results: a) by program; and b) by quarter based on the expected bundle end date. A minimum of 5 responses were required per bar for privacy reasons. In the quarterly run charts, each quarter's data are combined to create one bar in the graph. The first bar in the run chart consists of responses from patients whose bundle period ended prior to July 2016.

The percent positive response is also presented by a diamond-shaped point in the middle of each bar. For questions with four response options, the percent positive response is a combination of the two positive response options (e.g. strongly agree and agree). For questions rating their experience on a scale of 1 to 10, the percent positive response is a combination of response options 7, 8, 9 and 10. The number of respondents is indicated by a number at the top of each bar graph.

The Care Transitions Measure (CTM-3) is a scale calculated based on responses to three questions asking patients if their preferences were taken into account when deciding what their health care needs would be once they left hospital, if they had a good understanding of the things they were responsible for in managing their health once they left hospital, and if they clearly understood the purpose for taking each medication. Results for these questions are presented separately, as well as in combination.

Please Note: Programs focused on different patient populations and cross-program comparisons may not be valid for evaluation purposes. Moreover, some programs focused on less complex patient populations before scaling up, which may have affected early quarter results.



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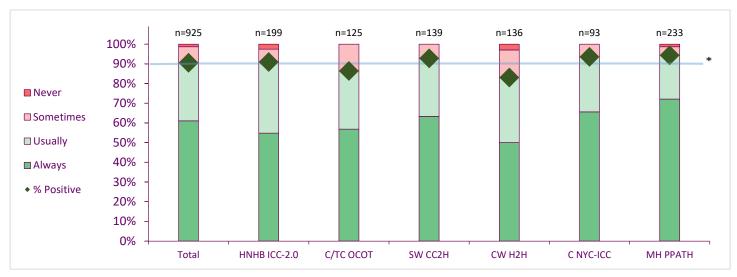
Section 1 - Patient Experience during the Index Hospitalization

Figure 1. The proportion of patients who reported good communication between providers about their care, July 2016 - July 2018

In fiscal year 2016-17, 90.2% of 32,475 Ontario medical/surgical patients selected *usually* or *always* to the same question on the Canadian Patient Experiences Survey – Inpatient Care (CPES-IC) (* indicated by blue line on the charts below).¹

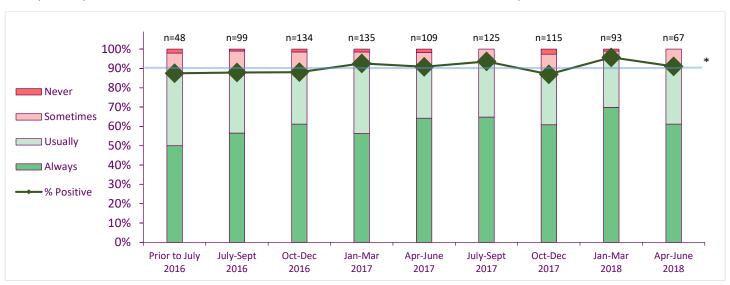
A) Cumulative By Program

Total percent positive was 90.6% and varied from 83.1% to 94.4% across the IFM programs.



B) Total By Quarter (n=925)

Total percent positive was 90.6% and varied between 87.0% to 95.7% over the evaluation time period.



¹ Aggregate CPES-IC data provided by the Ontario Hospital Association current to April 2017.

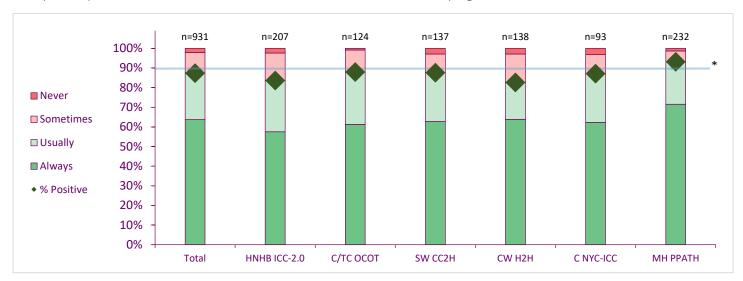


Figure 2. The proportion of patients who received all of the information they needed about their condition/treatment, July 2016 - July 2018

In fiscal year 2016-17, 89.7% of 32,538 Ontario medical/surgical patients selected *usually* or *always* to the same question on the Canadian Patient Experiences Survey – Inpatient Care (CPES-IC) (* indicated by blue line on the charts below).²

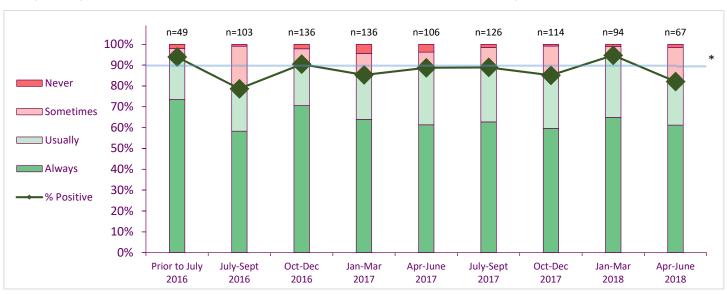
A) Cumulative By Program

Total percent positive was 87.3% and varied from 82.6% to 93.1% across the IFM programs.



B) Total By Quarter (n=931)

Total percent positive was 87.3% and varied between 78.6% to 94.7% over the evaluation time period.



² Aggregate CPES-IC data provided by the Ontario Hospital Association current to April 2017.

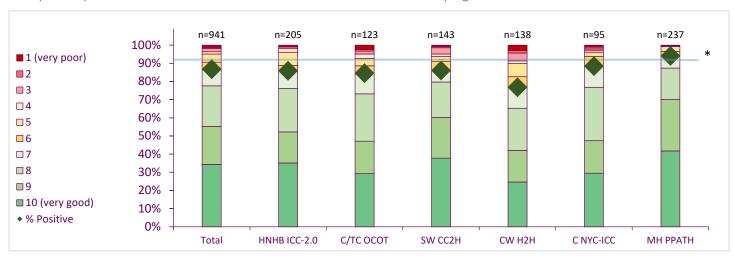


Figure 3. Patient rating of in-hospital care experience, July 2016 - July 2018

Results from 17,653 surveys completed by randomly selected adult patients who'd been discharged following an inpatient hospitalization in Alberta between 2011 and 2013 found a percent positive (rating 7-10) of 92% (* indicated by blue line on the charts below).³ On a survey of approximately 3.1 million randomly selected adult patients discharged from more than 4,000 hospitals in the US in 2015, 93% of respondents selected 7-10.⁴

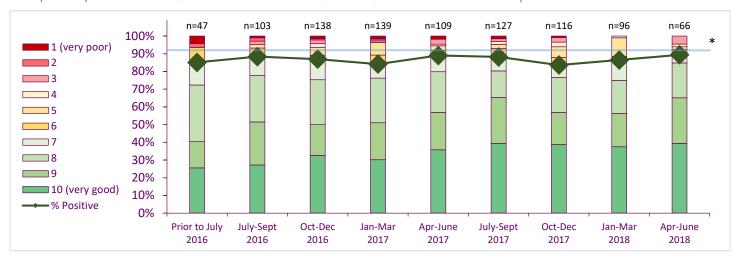
A) Cumulative By Program

Total percent positive was 86.7% and varied from 76.8% to 94.1% across the IFM programs.



B) Total By Quarter (n=941)

Total percent positive was 86.7% and varied between 83.6% to 89.4% over the evaluation time period.



³ Kemp, Kyle A., et al. "Drivers of Inpatient Hospital Experience using the HCAHPS Survey in a Canadian Setting." Health services research 50.4 (2015): 982-97.

⁴ https://data.medicare.gov/data/hospital-compare. Centers for Medicare & Medicaid Services, Baltimore, MD. Accessed 19/01/2017.



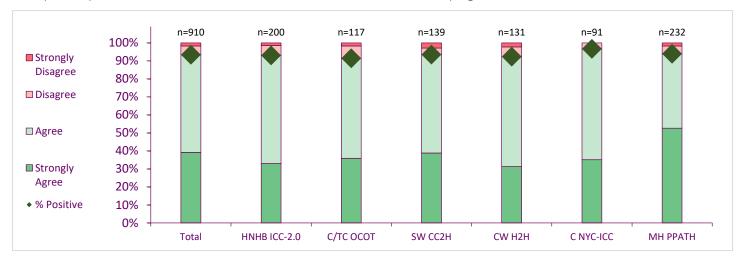
Section 2 – Patient Experience with the Transition from the Index Hospitalization

Questions for figures 4-6 were adopted from the Care Transition Measures (CTM-3), and Figure 7 presents the scaled CTM score based on these 3 questions. In a random sample of more than 3 million patients discharged from an inpatient hospitalization in the US from 10/2014-09/2015, the average percentage selecting "strongly agree" across the three CTM questions was 52%. For IFM patients, the equivalent measure was only 43.4%.

Figure 4. (CTM Q1) The proportion of patients who reported staff took their and their family caregiver's preferences into account when determining their post-discharge health care needs, July 2016 - July 2018

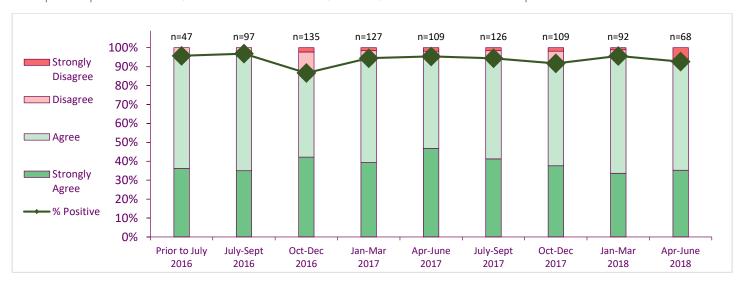
A) Cumulative By Program

Total percent positive was 86.7% and varied from 76.8% to 94.1% across the IFM programs.



B) Total By Quarter (n=910)

Total percent positive was 93.4% and varied between 86.7% to 95.7% over the evaluation time period.



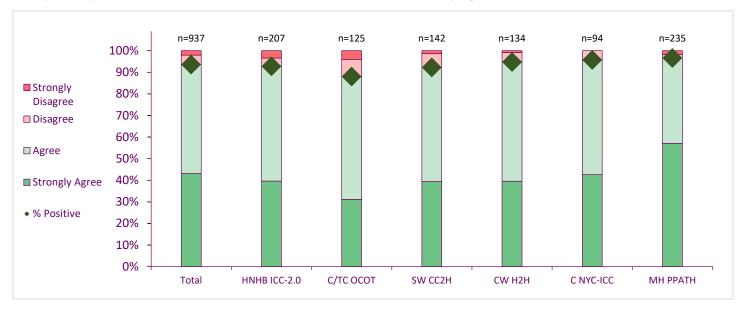
⁵ http://www.hcahpsonline.org. Centers for Medicare & Medicaid Services, Baltimore, MD. Accessed 19/01/2017.



Figure 5. (CTM Q2) The proportion of patients who knew what their responsibilities were for managing their health, July 2016 - July 2018

A) Cumulative By Program

Total percent positive was 93.6% and varied from 88.0% to 96.6% across the IFM programs.



B) Total By Quarter (n=937)

Total percent positive was 93.6% and varied between 90.6% to 95.7% over the evaluation time period.

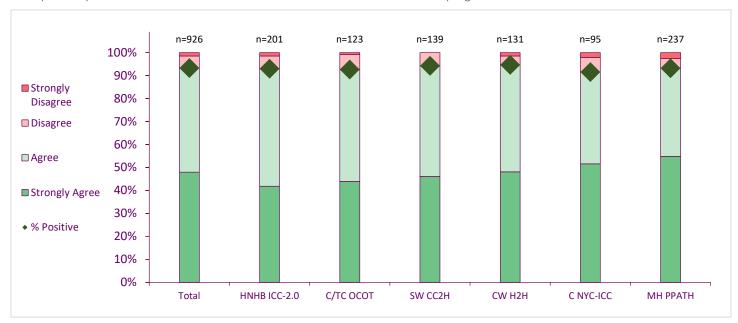




Figure 6. (CTM Q3) The proportion of patients who understood the purpose for taking each of their medications, July 2016 - July 2018

A) Cumulative By Program

Total percent positive was 93.3% and varied from 91.6% to 94.7% across the IFM programs.



B) Total By Quarter (n=926)

Total percent positive was 93.3% and varied between 89.5% to 98.5% over the evaluation time period.



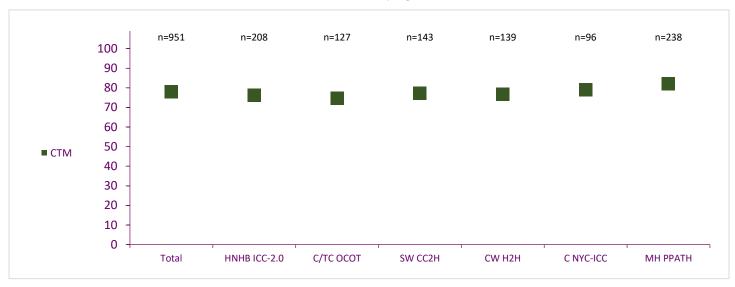


Figure 7. Patient score on the Care Transitions Measure (CTM-3), July 2016 - July 2018

The CTM-3 is a measure of the overall quality of the care transition; the higher the score the better the transition. This score is calculated by: 1) summing the responses to questions in figures 4-6, where a value of 1 is assigned to strongly disagree, disagree = 2, agree=3 and strongly agree=4; 2) determining the mean score; and 3) using a linear transformation to convert this to a score between 0-100.

A) Cumulative By Program

Total CTM score was 78.0 and varied from 74.8 to 82.1 across the IFM programs.



B) Total By Quarter (n=951)

Total CTM score was 78.0 and varied between 75.7 to 81.0 over the evaluation time period.



⁶ http://caretransitions.org/wp-content/uploads/2015/08/CTM-3-SCORING.pdf. The Care Transitions Program. Accessed 06/02/2017.

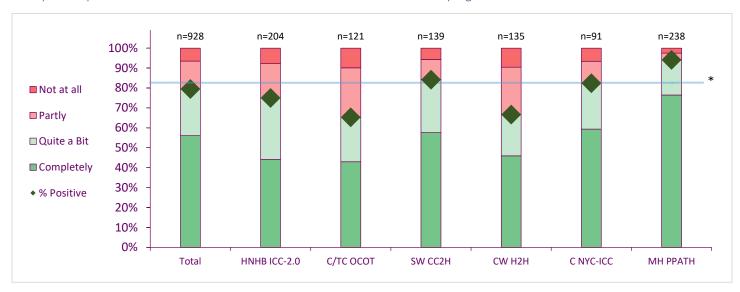


Figure 8. The proportion of patients who received enough information from hospital staff about what to do if they became worried about their condition after discharge, July 2016 - July 2018

In fiscal year 2016-17, 82.6% of 32,052 Ontario medical/surgical patients selected *usually* or *always* to the same question on the Canadian Patient Experiences Survey – Inpatient Care (CPES-IC) (* indicated by blue line on the charts below).⁷

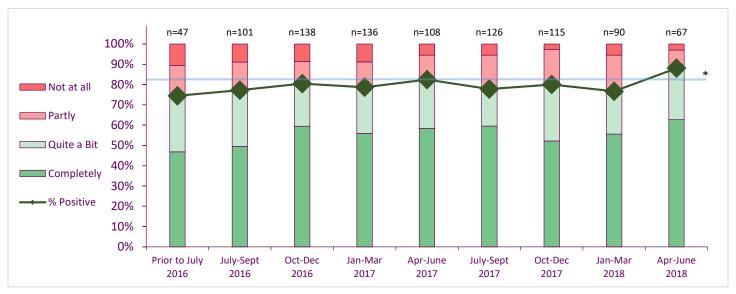
A) Cumulative By Program

Total percent positive was 79.5% and varied from 65.3% to 94.1% across the IFM programs.



B) Total By Quarter (n=928)

Total percent positive was 79.5% and varied between 74.5% to 88.1% over the evaluation time period.



⁷ Aggregate CPES-IC data provided by the Ontario Hospital Association current to April 2017.



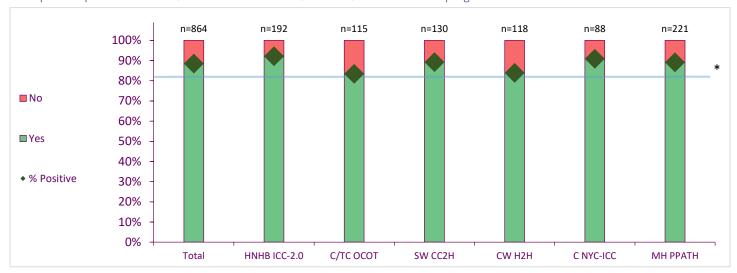
Section 3 – Patient Experience Once Back in the Community

Figure 9. The proportion of patients who reported that the providers from their usual place of care were informed and up-to-date about the care they received in hospital, July 2016 - July 2018

Around 85% of Canadian respondents (82% in Ontario) selected *Yes* to the same question on the Commonwealth Fund 2014 International Health Policy Survey of Older Adults (* indicated by blue line on the charts below).⁸

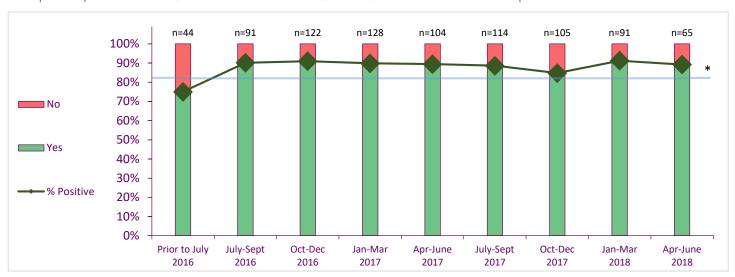
A) Cumulative By Program

Total percent positive was 88.5% and varied from 83.5% to 92.2% across the IFM programs.



B) Total By Quarter (n=864)

Total percent positive was 88.5% and varied between 75.0% to 91.2% over the evaluation time period.



⁸ https://www.cihi.ca/en/health-system-performance/performance-reporting/international/commonwealth-fund-survey-2014. Canadian Institutes for Health Information. Accessed 19/01/2017.

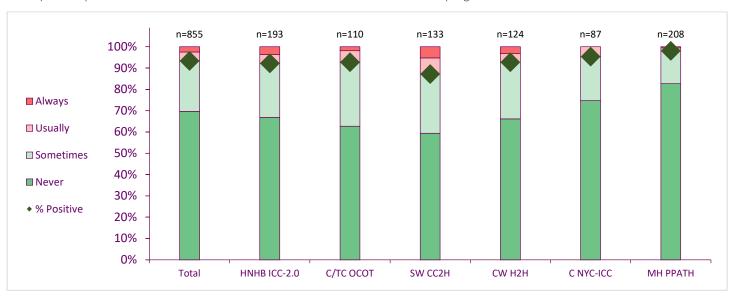


Figure 10. The proportion of patients who reported that a member of their care team was unaware of the changes in treatment recommended by another care team member, July 2016 - July 2018

This question was sourced from a Measure of Continuity of Care; data were only reported as a part of a composite measure and are, therefore, not comparable to our item-level results.⁹

A) Cumulative By Program

Total percent positive was 93.3% and varied from 87.2% to 98.1% across the IFM programs.



B) Total By Quarter (n=855)

Total percent positive was 93.3% and varied between 83.7% to 97.9% over the evaluation time period.



⁹ Haggerty, Jeannie L. et al. "Validation of a Generic Measure of Continuity of Care: When Patients Encounter Several Clinicians." Annals of Family Medicine 10.5 (2012): 443–451.

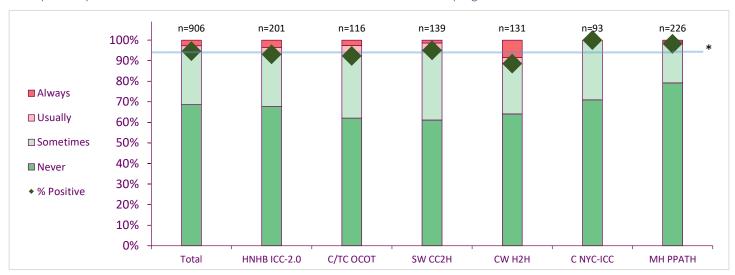


Figure 11. The proportion of patients who were confused about the roles of different service providers, July 2016 - July 2018

Around 94% of respondents to a survey of people with complex chronic conditions in Australia (n=767) selected *Never, Rarely,* or *Sometimes* (* indicated by the blue line on the charts below). ¹⁰

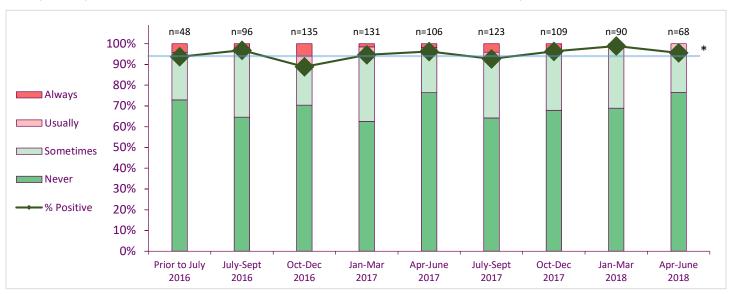
A) Cumulative By Program

Total percent positive was 94.6% and varied from 88.5% to 100.0% across the IFM programs.



B) Total By Quarter (n=906)

Total percent positive was 94.6% and varied between 88.9% to 98.9% over the evaluation time period.



¹⁰ McGuiness, Clare, and Beverly Sibthorpe. "Development and Initial Validation of a Measure of Coordination of Health Care." International Journal for Quality in Health Care 15.4 (2003): 309-18.



Figure 12. The proportion of patients who reported that members of their health care team were available when needed, July 2016 - July 2018

This question was modified from the St. Joseph's ICC Survey; data were only available to the Central Evaluators as part of a composite measure (access to care and convenience) and are not, therefore, comparable to our item-level results.

A) Cumulative By Program

Total percent positive was 95.1% and varied from 89.4% to 97.1% across the IFM programs.



B) Total By Quarter (n=906)

Total percent positive was 95.1% and varied between 92.5% to 100.0% over the evaluation time period.

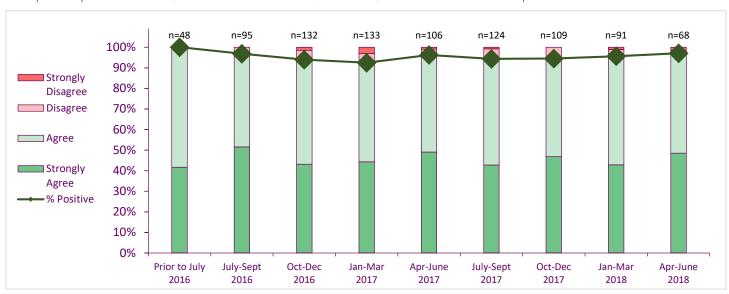


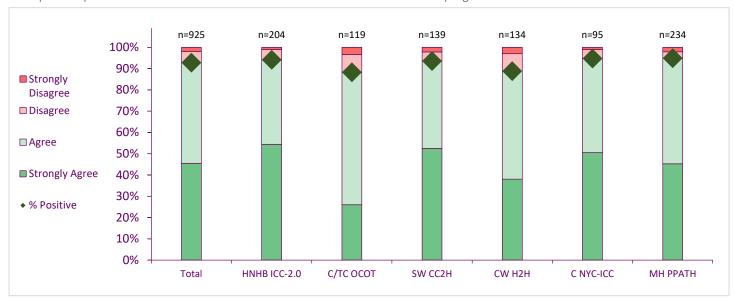


Figure 13. The proportion of patient who reported that their appointments and visits were arranged in a manner that was convenient for them, July 2016 - July 2018

This question was modified from the St. Joseph's ICC Survey; data were only available to the Central Evaluators as part of a composite measure (access to care and convenience) and are not, therefore, comparable to our item-level results.

A) Cumulative By Program

Total percent positive was 92.8% and varied from 88.2% to 94.9% across the IFM programs.



B) Total By Quarter (n=925)

Total percent positive was 92.8% and varied between 89.8% to 95.9% over the evaluation time period.

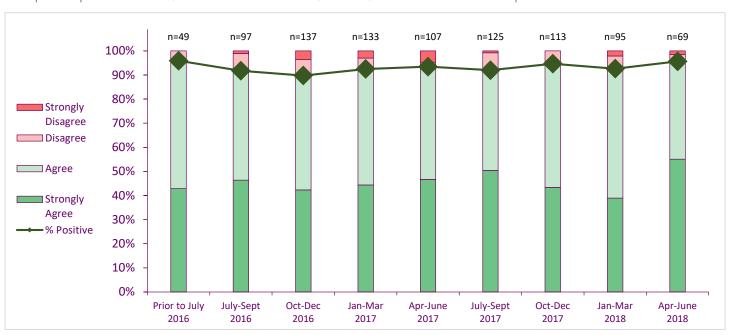


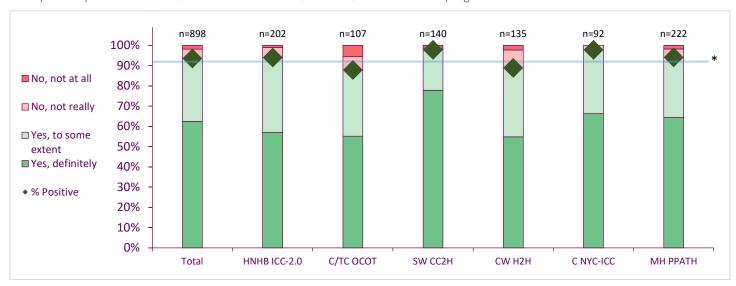


Figure 14. The proportion of patients who felt that the IFM program helped them feel confident in their ability to take care of their own health, July 2016 - July 2018

On a survey of primary care patients completed across Canada, 92% selected "Strongly Agree" or "Agree" that they were confident in their ability to take care of their health (* indicated by the blue line on the charts below). 11

A) Cumulative By Program

Total percent positive was 93.5% and varied from 87.9% to 97.9% across the IFM programs.



B) Total By Quarter (n=898)

Total percent positive was 93.5% and varied between 89.1% to 97.9% over the evaluation time period.



¹¹ QUALICOPC – Quality and Costs of Primary Care. Unpublished Raw Data.

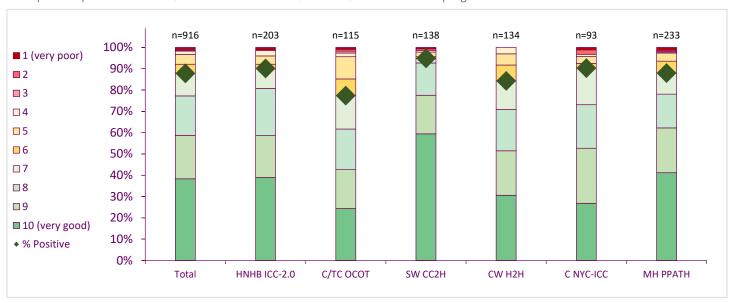


Figure 15. Patient rating of post-discharge home or community care experience, July 2016 - July 2018

This question is a modified version of a question from the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) presented in Figure 3 above regarding the overall hospital rating.

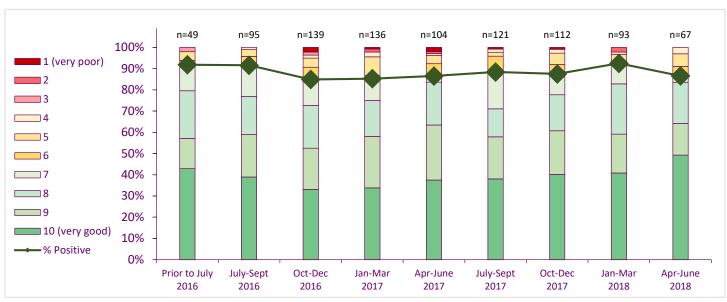
A) Cumulative By Program

Total percent positive was 87.9% and varied from 73.4% to 94.9% across the IFM programs.



B) Total By Quarter (n=916)

Total percent positive was 87.9% and varied between 92.5% to 84.9% over the evaluation time period.





Section 4. Patient Comments

Respondents were able to share any additional comments about their experience, either at the end or, for telephone surveys, throughout the survey. Only the final comments are reported below. Square brackets are used to indicate any words that were not transcribed verbatim at the time of the survey and have since been inserted.



HNHB - ICC 2.0

- 1. "It's nice to have a follow-up and to have someone else thinking about me. You are not alone in this world."
- "[I] have received excellent care from the hospital, CCAC, and DON, and have received all the care
 [I] need. Any program that would facilitate these services in other communities would be very helpful."
- 3. "We were very impressed, my wife and I."
- 4. "The program was excellent, did not have any problems with them coming to the house."
- 5. "[I] really liked it, have no complaints. [I] have numbers to be able to reach them at any time because they're always on call. The program is great for [me] personally. It should be extended to everyone."
- 6. "The program was good."
- 7. "When [I] first heard about the program, it sounded very similar to the CCAC, but [I] realized that it is a very good program. [I] wish that they were in Malden so they could take care of [my] elder sister as well. If this program was available in all areas, it would be wonderful for seniors. All members of the team were knowledgeable and professional. None of them tried to speak down to [me], which [I] appreciated."
- 8. [Caregiver's comments] "It would have been better if the PSW's could have come in the morning rather than the afternoon, so that he [the patient] could be washed in the morning. [We] were hoping that the nurses would come more often than they did. It would have been better for his care, concerns that we had. In one instance, a nurse came and she was looking for information that should have been on the iPad and wasn't. The program was great, it was great for [my] mom, a great help to her. The physiotherapist showed [us] all the exercises."
- 9. "The biggest concern I had was that the first 9 days in the hospital they told me nothing. I asked and they told me nothing. I went home then went back to the hospital and they finally told me what was wrong. Other than that it was good. I got a booklet on what I should and should not eat, and one of the cereals I shouldn't eat was cornflakes, but that's what they gave me. That's because I'm diabetic though. One of the things I liked about being in the hospital was that I lost 40 lbs, and now I feel great."
- 10. "It was very helpful. I enjoyed having people around me. I'm trying to follow the program that they gave me as best as I can. They were all very nice people. They seem to know their jobs."
- 11. "It's a good follow-up program. It's a good approach."



- 12. "It was excellent. All the people that were involved were great. [I] wish that [I'd] known about it sooner."
- 13. "I think it's great that everyone can be followed up on like this."
- 14. "It was ok for [me]. The hospital care was very good, the nurses, doctors and staff were all very good to [me]."
- 15. "[I] was very well taken care of, but the nurses only came every two weeks. [I] was nervous when I left the hospital. [I] have had multiple hospital visits because [I] couldn't breathe for various reasons, but after [I] was enrolled [I] have been feeling much better. [I've] had very good care. [I] was looked after, [my] cardiologist was very attentive."
- 16. "The program was good, but it was short. [I] thought the program would be longer. They should extend it."
- 17. "It is a marvelous thing. If there's any chance that [I] can continue the program [I] would jump at the chance. This team is the best and [I] have never had anything like it. The people are professional, classy, and a great team. Our citizens are lacking care."
- 18. "I think it's a wonderful program. Anyone that gets on it there is no reason that they wouldn't be satisfied. I hope it never goes away because if I ever needed them again they would be there."
- 19. "It was a good program. It did its best to keep people out of the hospital."
- 20. "It is a good program. A lot of seniors need help when they come out of hospital."
- 21. "I thought it was a very good program, if you have a problem they get on it right away and help you with it."
- 22. "The program was excellent. They were great. Had a nurse and nutritionist come in. They were excellent."
- 23. "Everything was great. [I] spent a week at the Juravinski spa."
- 24. "It was a great program. I didn't know we had that here, and that it was free services. It helped me out a lot, how to go about getting... I didn't know I was able to get cabs and stuff. They were always very, very concerned about my legs. The swelling just won't go down in them. They were always worried about my breathing."
- 25. "Was very helpful on different matters."
- 26. "Very well Thank you."
- 27. "I've been impressed with the way it was handled."



- 28. "No, actually, I was quite pleased with the whole set up. I was very, very scared in hospital and coming home from hospital, not knowing what I was facing, but knew that I was coming home with all kinds of help. Very tiring at the beginning with all sorts of people coming out of the woodwork. I think it's a wonderful program. Now I'm being transferred over to the umbrella of the community, under CCAC. I think it is an excellent, excellent program."
- 29. "The program is very good. I could have done that a couple of years back when I had some other operations. The problem I have is with the government, and that is with transportation. Before I went in to that hospital, I went in to urgent care in Port Colborne and they told me I needed to be admitted into hospital, then they were going to transfer me into Welland. I only have doctors in St. Catharines. The ambulance won't take me in to St. Catharines. They've closed all the hospitals in the area and moved all the doctors to St. Catharines. Any women in Port Colborne who goes into labour get transferred to St. Catharines. It's a crazy system."
- 30. "I enjoyed it. It was very helpful."
- 31. "It's interesting. I feel very grateful about the care I received. It comes down to if you are asked the right questions."
- 32. "I would agree with continuing, and indeed, expanding it. The nurses on my case were professional, knowledgeable, and most important (I think) cheerful and friendly!"
- 33. "I enjoyed it very much, really. They were very good. They didn't overstay their visits. When they said they were going to come they'd be right here. They answered any questions I had at the time. I thought they were very, very nice. All of them were very nice that came to me. They asked me to join the group. I could go to their office to talk about the program but I could not do that all the time because I would have to take the taxi."
- 34. "I think it was very good and I really appreciated all the help I get."
- 35. [The patient was admitted to the program twice within six months. The patient was asked to answer the survey with regards to the second visit to Joseph Brant Hospital. The timing and location of the first enrollment have been blinded to protect the patient's privacy.] "The ones [the first time] did a fantastic job, but the ones this time [during and after visit to Joseph Brant Hospital] didn't to a good job. I want to praise the other ones, and say that this one in September really should have maybe been... I wish they were listening in to how the ones [before] treated me, from the first lot I had. The ones this time could learn a lot from the ones [before]. I'm younger than a lot of the patients they might be dealing with. The biggest thing is that people explain properly what's wrong with you, this is what can help you, and how to do it properly. The [first] one did a better job than this one."
- 36. "I thought the program was pretty awesome, as was my stay in the hospital. Everybody was super nice. I don't have anything bad to say about any of the girls that came to the house. If you've got to be in the hospital, I guess it was a very pleasant experience."



- 37. "Overall, considering how many medical problems I had altogether: my heart, asthma, COPD, the overall care was very good. I wasn't waiting months on end. The services there, and as far as immediate emergency services, it's excellent. You have the best of the best, no matter what your illness is. On a one to ten scale, emergency services are a ten."
- 38. [Caregiver's comments] "She was discharge when she already had symptoms of a heart failure. Had to take her back to the hospital after two days to get treatment for her heart failure. Very disappointing for the services received in the hospital."
- 39. "Effective program."
- 40. "I had the most excellent care that anyone could imagine. Thank you from the bottom of my heart!"
- 41. "It was great. I would like to single out a few people for being excellent. This is hands down the best person they sent to my door: [the dietician]. She gave me the most information and she was willing to put it into an email so that I could read it. The second person is [the physiotherapist], and he was also great."
- 42. [Caregiver's comments] "I thought the program really helped to understand the way to use his prescription and when to take them. We thank you very much."
- 43. "[Caregiver's comments] Excellent program/services. Helped my mother immensely. Thanks."
- 44. "Program was very good, overall. But the hospital food was not too appetizing. [The patient] asked if he could have a shower, they said that the showers were plugged up (4 weeks)."
- 45. "Excellent Program!"
- 46. [Caregiver's comments] "This program gave us vital information about pro-active health care. We learned so much about COPD itself, as well as resources available to help prevent another hospital stay. A very sincere thank you for this outstanding program!"
- 47. "Fantastic program. Should be extended in cases where recovery exceeds 2 months."
- 48. "Generally all involved were very good in and out of hospital. Received plenty of health care education materials and was impressed with the competence of the ICC nurse program."
- 49. "In the last 3 years starting with the quad bypass, St. Joe's, Juravinski and the General have saved my life; very literally, about 10-12 times, with style and grace. They are world-class hospitals, with world-class facilities and world-class doctors, nurses and other support staff. I walk into ER thinking I'll leave by the dumpster out back, but they fix me up, explain things to me, and send me home again. I get the same treatment the Queen would get. That goes for EMS as well. I've called them 3 times. Once when they couldn't come right away, the fire department came and put me on oxygen. What I see consistently is world-class training, documented results, and positive attitudes.



I've never heard a raised voice from any hospital personnel. I do hear lots of laughter from them. The first time at St. Joe's 3 years ago, in the clinical training unit, it was like being looked after by a whole flock of pretty granddaughters - but trained and disciplined. I've had an occupational therapist, physiotherapist, nutritionist and nurses visit me at home. Very practical and professional. The nutritionist [name removed] walked me through salt problems in my fridge, freezer and cans on shelves. That was an eye-opener, and I've cut my salt intake right down, with good results re: CHF. I'm in "non-compliance" regarding prescribed beta blocker, statins and prils - they destroy me. But I do take furosemide, metformin and ASA81. When I go to the hospital I say 'Thank God I'm Canadian.'"

- 50. "They talk to you like you went to the same school."
- 51. "I think the program is very helpful when I came home from hospital. I have a scooter now, help paid for by Ontario Health program. Thank you Canada Health Care."
- 52. "ICC Program was excellent. They helped me more than the hospital staff (Doctor & nurses). [Provider name removed] and his team were very helpful."
- 53. "[Provider's name removed) has been superb since my 3 week stay in hospital in Aug/Sep 2016. She was also there for me in Feb 2017 when I left the hospital (2 months ago as per survey)."
- 54. "Thanks for all the help."
- 55. "It was much appreciated and necessary to have help in my home upon leaving the hospital. It helps other family members who take on the responsibility in addition to their daily jobs. Thank you."
- 56. "Note: I do not recall having been informed of my association with the SI CCA HNHB."
- 57. "St Joes is a very good hospital with good staff and Dr.s. All my Dr.s confirm with each other."
- 58. "Thorough related, very thoughtful much more."
- 59. "Everyone was ok nurses really helpful."
- 60. [Caregivers Comments] The program was excellent and made my father feel valued and cared for.
- 61. "Very Good Programme. Enjoyed most visits."
- 62. "After hospital stay (three days in hallway) the home care was not necessary for me."
- 63. "I think its fantastic and would like to see it more than 2 months, I think its great service."
- 64. "One home-care nurse was not well versed on medications I was taking or their use or side effects."



- 65. "The hospital care stunk, if you are able bodied do not go to the hospital. My blood pressure had gone up. I used to be a nurse. I was only given a Tylenol once, I got my bed changed once. I was put in isolation which was pretty stupid, and putting the curtain around me wasn't isolation. I was going to sign myself out. I wouldn't recommend it to anyone. The night nurses were great though. You can't fault the hospital for your roommates, with the aging population its pretty pressed to put you in a wardroom. The worst is they let the people sleep all day and the stay up all night."
- 66. "Excellent care after leaving hospital."
- 67. "I am a lucky man! And received excellent help and support! Excellent nurses! Excellent doctors!"
- 68. "Some questions were confusing because I have multiple health problems. Concerning the program, I was given excellent care and information that dealt with the issue that I was hospitalized with."
- 69. "Excellent program, appreciated. Sorry I am late submitting this. It is hard to see my family doctor without a 2 week wait. Those who came to interview me were able to share information that was valuable to me."
- 70. "Thank you. This is an excellent program and so far the experience has been very good."
- 71. "The program I got after I left the hospital was fine. I ended up turning back again, and went to St. Joseph's because I wouldn't go back to Juravinski."
- 72. "If program is temp visiting by nurse/paramedic, it was very good and helped prevent ambulance visits to hospital (911) and emergency room. Should be extended in some format."
- 73. "My at home care is excellent. My only complaint was my emergency care. The front line staff were great, considering what they had to work with. I was on a gurney for 30 hours, waiting for a bed. There were 20 patients ahead of me. That was a nightmare when you are so sick. I didn't eat and drank sparingly because I didn't want to bother the busy nurses to ask for toilet facilities. A simple fitted sheet on the gurney would have made a huge difference."
- 74. "The one thing that happened is the hospital took me off my high blood pressure. The result was me being sick and my general practitioner had to figure it out."
- 75. "Great services."
- 76. "Very good program!"
- 77. "Was pleased to have visiting nurses, dietician, therapist, etc. To know they were continuing and could answer all my questions, without my having to phone physicians, etc. or to just keep wondering."
- 78. "Good experience."



- 79. "Very pleased this program was available to me."
- 80. 'They were all lovely."
- 81. "I just like to say how very lucky I am that I do live in Canada, and the community, where there is such incredible resources, and I'm really proud of the healthcare services we have here both in hospital and with the home care. I am very grateful for that."
- 82. "My hospital stay was ongoing. Dr. [Redacted] the Best! Also all others were great. The nurses were great! My COPD care afterwards was Great! [Name redacted] who set it up was so explanatory and everyone was fantastic with me even ambulance people, love them all. I thank them."
- 83. "My only complaint was too cold in hospital, no heat, my daughter brought me sweater and 2 blankets from home but didn't help."
- 84. "Therapist good but not necessary. Nurses etc. were good. Didn't need dietitian. Could have been "same" nurse each time. Each gave different opinions contrasting the other. Really I didn't require a nurse as I did my own blood pressure, weight etc. myself. I really feel I wasted their time as I didn't need the extended care. They were all polite and caring. My Doctor could help me the same way."
- 85. "The outpatient program was very helpful. I think it's a good thing to have directions when you come home."
- 86. "The patient mentioned his life-course as being a difficult one, having only a 6th-grade education, dyslexia, spending time in the children aid society and having been incarcerated. Patient strongly prefers 1-on-1 therapy rather than group sessions. He was told not be emotional as it will exacerbate his COPD, which is difficult with all the trauma in his past and his current mental health issues as he feels misunderstood by society. The patient would like a more tailored care pathway that suits every patient's personal circumstances and needs and a relationship with his care providers."
- 87. "The ICC program offered and gave more help, support and information about my illness than the hospital and family doctor. The ICC made me feel safe in my home after the hospital. I live alone and various staff that came in made me feel checked on and safe and reassuring of health improvement. Part of discharging planning was to see a respiratory specialist; no referral was sent. ICC followed up and got the referral to the specialist. Can't say enough about how good ICC was for me!"
- 88. "Overall I think it was a very good thing that they started, or however long it has been running. I like the idea that there was someone coming to your house, a physiotherapist coming to your house. I really like the idea."



- 89. "I found that I really didn't need all these people coming. When I was released from the hospital on Friday, which I shouldn't have been. The next day it was a total turn around and I felt great. But then I had all these people coming to my house and I felt that it was a waste of my time and theirs."
- 90. "Its good."
- 91. "Always treated with respect!"
- 92. "I would like to emphasize that the medical staff at the BGH especially "INTERNS" were very helpful during my stay to really explain my CHF condition and its shortcomings."

SW - CC2H

- 1. "[I] support the program, it helped [me] adjust very well after [my] stay in the hospital. [I] had 28-30 days of the team coming in and would recommend it highly. [I] thought it was great."
- 2. "It's a very good program; very beneficial to me and my wife. Where it could improve was the nurse that was looking after me suggested I should go to the hospital to check the heartbeat and blood pressure that were out of whack; when I was at hospital during the triage, they figured that I had a diarrhea and wished to conduct a stool test before anything else could be done after the diarrhea had cleared up and there was no stool to be examined. For this, I spent 96 hours in a very cold and uncomfortable environment, that would have been eliminated if the nurse had contacted the hospital and arranged exactly what I was coming in for. That was very detrimental to my health. I spoke very highly of the services I received at Victoria hospital, but this incident was scary. The doctor prescribed that I put on the inhaler every 4 hours or as needed, but when I asked the nurses to leave the inhaler with me so that I could put it on, they took it away every 4 hours and wouldn't give it to me until the 4 hours were up. There should be some bridge between emergency department and home care system for a short-cut system. Getting into the emergency room was kind of ridiculous. The government should know that Hydro increase affects patients too; the air conditioning needs a higher rate to maintain a liveable environment."
- 3. [The patient doesn't know if the program is still running, or if there's anyone else coming to see her. She mentioned that she was confused.]
- 4. "Overall it was very good. It's a good step."
- 5. "[I] think very highly of the program, [I] think it is an excellent idea. [I] felt much more comfortable at home, rather than in hospital worrying about what bugs [I] might pick up."
- 6. "I was anxious to leave the hospital because I was a bit afraid of falling. The program they hooked me up with was excellent. I could not have asked for better care after I came back from hospital. They were very, very good."



- 7. "The program was a real blessing. Other people with COPD are given puffers and sent on their way when they visit the doctor. [I] learned a lot about managing [my] condition by talking to the nurse. Without the program, [I] would be back in the hospital and would be ignorant about how to treat it. The program gave [me my] hope and [my] life back. [I] had major depression and thought [I] was going to die. [The] program not only checked [my] vitals but also gave [me] hope. Personal support workers, [I thought], were better than the psychiatrists. [I am] very grateful for the program and [I] can now spend time with [my] grandson. [I] hope this program will benefit others and it should be expanded. Members of the team were compassionate and didn't just focus on illness. They also spoke to [me] and encouraged [me]. Due to [my] condition [I] lost a lot of weight, but [my] healthcare team made sure [I] ate well. Overall, [I] trusted [my] doctors and nurses, felt very safe and thought that the team was very honest. Without the program, [I] would be a mess."
- 8. "The program is good. Patients will feel good and it is a really big help. Caregivers will be helped too and they can call the healthcare team. Calling the nurse (24-hour service) helps [my] daughter feel calm."
- 9. "[My] family doctor seemed confused, but this was due to him and not the program (they reached out to him several times). [I] didn't know the program existed until [I] was in hospital. It was a fantastic program. It has made a huge difference for [me]."
- 10. "The program was excellent."
- 11. "All I can say is from the time I entered the medical system, all the care and attention I received was awesome. Thanking all of you."
- 12. "The therapists were friendly and kind."
- 13. "Too much information given and fast. Overall very good care and I have a number to call when I need it"
- 14. "[I] think it's a good idea for people who have COPD to take advantage of it. [I] was not given one of [my] medications at the hospital which made [me] wired and uneasy, but [I] felt better after the nurses came to [my] home. [I] was told that [I] need to monitor [my] condition to make sure that [I] don't have another episode, [I] was given lots of information and an iPad to help [me]."
- 15. "[I] liked the program very much."
- 16. "I would recommend this program to all leaving hospital. It is extremely well run and informative. My life has improved greatly. I am more self-sufficient and stronger. My staff serving me was wonderful and well informed."
- 17. "I got good care at the hospital, but the care at home was better than [I] had after [my] heart surgery. It was good care."
- 18. "A very good program."



- 19. "I was a bit disappointed in it, the fact that I ended up twice back in the hospital. I was under the impression that I was under the care of nurses and not just PSWs who could decide if I needed to go to emerge. That was disturbing to me."
- 20. "The health care people in the hospital, and at my home for 28 days were excellent."
- 21. "You know when you feel sick and you don't feel well. Maybe it took too long in the home you have nurses and OTs coming in the home. Maybe for the OTs it was fine, but it did not need to be 45 minutes for the rest of them. When you have three of them coming every day, sometimes it gets too much. I don't feel it was their fault, they would have to sit when they were done. They would have to log in everything through their phone and that took a little longer than it should."
- 22. "The program is wonderful, everyone was very kind and helpful. If this could be done all the time to keep seniors in their homes."
- 23. "I enjoyed the visits by the team. They were very encouraging with regards to my recovery."
- 24. "This is a very helpful program."
- 25. "The first four weeks were good, the second stage so far has been non-existant."
- 26. "Thought it was excellent and changed the way I took care of myself. Gave myself and my wife a lot more confidence."
- 27. "I think it is a great program and should be continued. After speaking with others who were supposed to get home care after leaving hospital, it is a much better program than others got."
- 28. "Program was excellent. People care and provided services and direction. Activity and pain is associated with a fall on ice and hair line (#'s to ribs), but almost healed!"
- 29. "Other than the initial visit to the emergency, which was poor, the rest was excellent. I was not impressed. What they provided to me and the information that I got from it was excellent. I had a very good experience with the staff in the after-care program. It was excellent. I encourage the Ontario government to keep it. It will get people out of hospital and back into their own homes where they're comfortable. I know there were more things I could have had if I wanted them at no expense to me, but I didn't need them at the time. Hopefully I won't. 5 years from now I may need that help, that's why I encourage the government to support the program."
- 30. "Love it! This program is top of the line. So much better at home for comfort and care. I can't praise it enough. The medication maybe should have gone longer as it came back 3 days later and I had to get another perscription from my doctor. P.S. Question 32 on page 17 I get very bad back pain depending on what I'm doing. Nothing to do with this COPD or care I received. I manage it too."



- 31. "CCAC is a great group of professionals. Taught me a lot of info for COPD. They keep me well informed. LHSC is a great hospital. Glad it is close by."
- 32. "This is a top notch program. Very professional. Each caregiver was very pleasant and never rushed. I am so thankful that I was picked by Connecting Care to Home. Thanks to all."
- 33. "This program was really helpful after discharge from hospital. Real caring bunch of people."
- 34. "The program is a very good program in helping the patient getting home sooner & getting in home care, but some parts of the home care are repetitive & can be annoying."
- 35. "The home care team were excellent and well informed. We appreciated them very much."
- 36. "CC2H Care Coordinator [Provider's name removed] has been fantastic! Needed much more PSW assistance at first."
- 37. "I was always amazed at the quality of people whom attended to me."
- 38. "I have raved about this program with friends and extended family and I hope the government will continue to support and promote its continuance in other communities."
- 39. "Special thanks to my daughter. For helping me!"
- 40. "I have nothing but the highest praise, for the care I received during my hospital stay. Even more praise, for the fantastic care when I was released home. The connect care team, really, really helped me, and were wonderful."
- 41. "I think it's a good program, and I got to admit, this time in the hospital I was really, really pleased. Even the doctors were really good. And the people that come in when the real doctor doesn't come in, they were really good. And the home care thing that I'm on now is really good. The only thing I have with the home care is that it closes at 4:30. Sometimes when we need them it's later than that. When you're struggling some days and you're lightheaded or something and you don't know what's going on and you can't get to anyone, you think OK I've got to back to hospital and you don't want to. Whereas them guys can usually talk you through something, like I didn't know I had anxiety but I guess I do. I guess this caused it too because it's all new to me. I was going gangbusters before. I have no qualms with the hospital or home care. I think this is a good survey if it helps them. I think it will be good for everybody involved."
- 42. "My doctor didn't participate in the conference call. I would like to say I appreciated all the time & effort expended on me after my hospital stay. It is very reassuring."
- 43. "Basically communication with patients and clients in relation to scheduling and timetable. Options on more than one area of visit, e.g. physio or therapy for example. There was an e-tech visit everyday, I thought that was unnecessary. You're on the tele-health program and that could've been in conjunction with the program. They could be weaning people off the e-tech, they gave me



an extension for two weeks. More flexibility. But I think its very important that timing of appointments be communicated. When they did come, it's exhausting. The other thing is continuity, that person gets to know you. There is a rapport that is created. Someone new, not so much. I had an e-tech [name redacted], she was amazing, she was consistent, I think that's really important that's a big part of support. If your going to the hospital, it's the best place to get sick, my doing this program at home, you're significantly reducing the cost factor of hospitalization."

- 44. "Great!"
- 45. "Care has been excellent throughout my medical crisis."
- 46. "I was very impressed with the services provided by the Home Care Team visits. They helped me sort out medications initially and established a routine for my home care which I follow closely. Their efforts certainly contributed to helping me in taking care of my heart condition."
- 47. "The program was great, helped me so much!"
- 48. "Arrived home about 4 PM, Thanksgiving Day. First program leader called at 9 AM next day and arrived in the morning. Liked this lady who was competent, friendly, explained program. Had people every day re exercise blood pressure, etc. I was impressed and as my first heart problem felt that I had people to answer any questions. Excellent program!! And now have telehome care set up at my house."
- 49. "1) Am now on oxygen line, mobility limited unless use ox. Thanks. 2) Hospital doctors were lax on informing my family doctor of my illnesses until 2-3 weeks after discharge from the hospital. 3) Shortage of R Nurses in hospitals. 4) Only 1 therapy person for 2 floors of hospital so limited use of exercise for walking."
- 50. Great program home family/friends to be involved health issues, one to one experience better then group; 24/7 contact for info: need or don't go to hospital / just to talk/follow up; Independence of self-care home *Program should continue*
- 51. "I was very happy with hospital staff and the home care team they taught me a lot."
- 52. Resident prescribed Potassium of 300mg x 2 per day causing low BP & heart rate which required 2nd hospital stay. Now don't trust doctors.
- 53. "I was very pleased with the Connecting Care to Home service."
- 54. "Home program I felt was very good. Hospital staff is a different story, only 1 or 2 bad apples."
- 55. "I feel I have to make some comments in regards to this new program, which I understand are meant to reduce cost and make more room in existing hospitals in Ontario. I fully understand the idea and think it will be successful, provided you make some small changes. 1. I am 80+ years old and so is my wife of 60 years. We have been retired for a long time and enjoy this part of our lives.



- 2. We both feel that your "home staff", nurses for this program, need to be instructed on how to make their visit/appointment to the homes, i.e. in our case we started out having your program staff arriving unannounced at 8:30-8:45 in the morning, a time we both enjoy by sleeping "late" and I finally has to tell your nurses that they, when making the next appointment has to make a selection between 11AM or 2PM, so we would be able to do our own planning for the day. 3. We also felt that the same questions were asked by the staff at every visit to our home and if that is all the information that is needed, that information could be given via a phone call, thus cutting time by eliminating/reducing the traveling of your staff, thus time to visit more "customers". 4. Of course, these questions might change and the "customer" might require more help, however that could easily be determined during the first few visit to the home."
- 56. "I'm quite satisfied with the care at home from the healthcare workers. They were very courteous and I was very glad to see them. I looked forward to their visits."
- 57. "The Connect Care to Home is a valued program & a relief to have contact with as opposed to going through the emergency."
- 58. "I thought the program was a BIG help. I was discharged from hospital the day after pacemaker implanted so I was confused and needed help. The connect care people were very helpful. I would have been lost without them."
- 59. "I learned a lot and could ask questions. I could try out new ideas and do my exercise. How to breathe properly is very important. That I remember."
- 60. "The staff were very good, and helpful."
- 61. "The healthcare I've received since I've been in London has been amazing, I can't believe it. I have a friend in [city] and its terrible for her. The care I've received has been excellent. In fact, even the healthcare leader just called me yesterday to see how I was doing, very conscientious."
- 62. "It was a great program and very helpful."
- 63. "It was an excellent program."
- 64. "The information provided by the respiratory therapist + nurse was very useful in learning to live with COPD."
- 65. "Connect to home care was of great help to me. Living alone knowing I have a 24-hour phone line gave me some relief."
- 66. "The programme Connecting Care to Home was a helpful programme & gave my wife & I confidence we could cope with health concerns & daily lifestyle changes."
- 67. "Thank you for the CC2H program. It really helped me. Please keep funding this excellent program."



- 68. "The doctor at the hospital was useless and no help. Nurses were wonderful. My biggest worry was my husband who resides in a nursing home with dementia and he did not understand why I did not visit."
- 69. "Overall, an excellent home care program. A little overwhelming in the beginning, with so many workers coming in but very informative."
- 70. "I have to be honest with you, I was taken well care of by the doctors and nurses, and I have no complaints. They saved my life."
- 71. "I love this program as it helps me understand my illness, as well as the workers are so caring, I think for people my age this is a perfect way to stay independent in my own home."

C – NYC ICC

- 1. "Half a loaf is better than nothing. Keep the program going forward. Anybody can get something out of it if they have a serious interest in participating. I welcomed it and was glad that I participated. I would like to have a cleaning service to help me, if they were able to clean properly."
- 2. "I felt very benefitted from the care program. It made me more aware of my body changes and reactions and the importance of exercise and keeping fit. \$300 over 8 weeks is a lot of money, but it was still well worth it, which was for the therapy after my COPD program."
- 3. "The exercise program was absolutely wonderful, [I] was lifting 5lb weights and doing 30 min on the bicycle, even though [I] thought [I] wouldn't be able to lift even 1lb. [I] felt exhilarated after finishing."
- 4. "The program is wonderful, it was a great program. It should be continued in some way, after enrollment is over. [I] would have liked help with exercises after [I] ended the program. [I] would like an additional program to help the patients continue. [I] would like to participate in a fitness program, but [I'm] limited in mobility by an oxygen tank, and it is very difficult for [me] to arrange on [my] own. Eight weeks is too short."
- 5. "I was treated like a king at North York Hospital by all medical persons who treated me, and all serving staff. Thank you doctors, nurses, attendants."
- 6. "[I] don't feel in the best condition, [which] makes [me] a bit depressed. [I] have had a few flare ups since being admitted. Overall, the situation is somewhat under control. Since [I] left hospital, [I] decided to enlist the services of Phillips Life Line since [I] am home alone, in case [I] get a flare up. [I] need to pay a monthly fee, but this is difficult since [I] am retired. [I] would like if some of it could be paid by some government agency."



- 7. "It's a good program."
- 8. "(1) At this time I am partially incapacitated for reasons of suffering from arthritis. (2) I am (together with my wife) living in an assisted living facility."
- 9. "There was a different helper every day, [I] had to re-explain/re-train them. [I] had trouble getting transportation with C-care service [I-rider?] because [I] needed to have a caregiver with [me]. Then [I] had to get a family member to drive [me] to and from appointments."
- 10. "[I] had a very delightful nurse throughout the program, who looked after [me] extremely well, advised [me] in great detail, and pushed [me] into looking after [my]self. The head of the program at the hospital was also terrific and checked up on [me], kept [me] up-to-date. Overall it was great."
- 11. "I think it's very good. It was a nice, extra piece to the treatment."
- 12. "It's excellent, the treatment that [I] received in the hospital and the follow up treatment were excellent. [I] had reservations about NYGH and this program changed [my] opinion."
- 13. "I am so thankful for the care and guidance from [the Client Care Consultant] from the North York Central Integrated Care Collaborative Program. This program has been one of the main reasons for my successful recovery. As well as the wonderful care from [the cardiologist]. If this program had been available when my wife had heart failure 2 years ago, she might have lived longer."
- 14. "This program helped relieve the fear or anxiety I had in the hospital due to my illness."
- 15. "In terms of my oxygen therapy with RESP, fabulous. Absolutely fabulous. In terms of this pilot project that I've been in, just great. My dilemma was that they didn't know what was the matter with me. So I had four unnecessary weeks in another hospital, airlifted down to this one, and they still have a funny diagnosis. The overall is just great. I do hope this program continues. The only thing that I would say, I'm a retired social worker, when watching people in the lectures, they would benefit from a support group. The sharing of concerns on a personal level with a qualified leader would alleviate this for some of them. I've been very fortunate, but some of them are very needful and live alone, whereas I don't. Hopefully this program will continue to be funded, that COPD gets a boost of publicity and education. Several people that should be knowledgeable have said "What's that." If it's going to be a blanket-type diagnosis following pneumonia, emphysema, etc., people need to understand better. I would not be in this mess if people had paid attention twenty years ago. These pilot programs are so hard to get started but the grassroots does appreciate it."
- 16. "The program is excellent and very educational. It is unfortunate that it is not longer."
- 17. "It's very nice, the nurse was very good, so I have no complaints in that respect. They only have to find someone in the hospital who can help wash you."



- 18. "I think its a good idea, perhaps not for me right now because I've only just started with COPD. It's not like I've had it for a while, so it's not as helpful for me right now as it will be later on when it deteriorates. I think it's a good idea overall. I think the networking among the various providers is very good because you don't get that with a lot of illnesses, especially the fact that it involves my own doctor. The communication is very important amongst the different providers, because you don't always get that. I had an experience last summer with an unrelated problem, and it can be a nightmare if nobody communicates."
- 19. "This program has helped me to understand and take better care of myself."
- 20. "It was very good, I'm very satisfied. I'm glad I went to the program. Thank you."
- 21. "8-week program was great, so glad to be involved. Hospital care and communication about condition of patient was poor."
- 22. "I think this program is designed for people who are retired. It's designed for people who don't work. It's a great program, but there's got to be a better way to work it for younger people who participate. The nurse on her last visit said that she felt like she was wasting my time and in my way, which wasn't true because she was available to answer my questions, but it was hard to schedule her into my schedule. Need to consider that sometimes you'll have people who are considered younger."
- 23. "P.S. I saw the Dr. only once to tell me I could go home, this was the 5th day of my stay in the hospital!"
- 24. "I am delighted that I have taken part in the program. I find the exercise group so helpful and the staff so pleasant. I have much more energy."
- 25. [Caregiver's comments] "We've had a very positive experience."
- 26. "Follow-up pulmonary rehab program at hospital very helpful & definitely worthwhile. Highly recommended!"
- 27. "Very pleased with NYG."
- 28. "I feel very lucky to have been offered this program. A wonderful experience. Learned how to handle my COPD and realized I am NOT too old to exercise."
- 29. "1. NYGH: Protocol blood thinners administered causing internal bleed. No one noticed. Assigned doctor never saw patient, only seen by residents (rotating in/out). Stroke occurred as a result of angiogram, atf, never noticed by nurse. Relatives noticed stroke symptoms and when reported to nurse, she belittled them as being overprotective. Critical care team called but could not do anything. No one called stroke team. Family did not know about a stroke team at NYGH until a speech therapist mentioned it toward the end of the stay. Also, visiting rules were not followed, so patient was disturbed by neighbour's visitors after 10pm until patient complained twice, then was



moved to another floor before discharge to Providence Rehab. 2. Providence Rehab: Doctor's hours minimal, hard for patient and family to see doctor. This facility is not equipped to handle patients with underlying chronic conditions who need rehab. Not enough medical oversight. Not enough discourse about effects of stroke with patient and family. Recommend: after initial assessment, case management discussion with patient and family on the particular effects of stroke as it pertains to the patient. Timeline of rehab stay is determined by a gov't driven algorithm. This timeline did not match patient's needs. Discharge date too aggressive. 3. Sunnybrook: Doctor suspected delirium due to age of patient. On last night, patient was moved to hallway with belongings, without hearing aids or glasses. Left near nursing station to sleep. In the morning, family found patient in a chair, in shock; no one had given the patient the hearing aids or glasses to put on. The room was utilized by someone else. All the gains the patient had recently achieved were lost as a result of this incident. Overall, patient treatment at all these facilities needs to be overhauled. The way patients and their families are treated as persons by staff, needs to be improved. Information needs to be shared with the family more easily. Additionally, the parking fees at Sunnybrook and NYGH are offensive. They are prohibitive and negatively affect the situation of a hospital stay. They need to be reviewed and the fees lowered."

- 30. "The program is a phenomenal, excellent program."
- 31. "I had the pleasure of having my cardiologist at the hospital every morning, my GP phoning me every 2nd day. I was well taken care off. Nurses were fantastic. My family very supportive. Through the help of the heart function clinic, which I attend once a month, I have helped myself to diet, exercise, independence, etc. Thanks to everybody above. My only beef is the beds and food."
- 32. [Caregiver's comments] Patient has no comments, but I (the daughter) would like to say that the support provided by the program made me feel more confident that my Dad could stay home with me, that there was always someone I could contact with concerns. A+++!
- 33. "We appreciate the guidance and support provided by NYC ICC team and the supportive care team at North York General Hospital."
- 34. Sometimes caregiver's English was poor especially over telephone. This was poor pronunciation
- 35. "Wonderful COPD Program at North York General. [illegible] amazing."
- 36. [Patients comment] "Thank you." [Caregivers comments begin] "Parking is expensive. Tuesday start time is close to lunch so have to buy it at the hospital. Physios do not coach and assist the participants enough to ensure exercises are done properly, they spent most time chatting amongst themselves or using the computer. Would be helpful for the program to have a walker available."
- 37. "1. You should reimburse us for Transportation (i.e. TTC tickets). We are on a fixed income. 2. The exercises with weights around the ankles are too many and too strenuous. In the last week I could not attend due to swollen ankles and a very painful right leg which I could not lift."
- 38. "This was a costly experience: PARKING"



- 39. "Upset by care by cardiologist in emergency. Prescribed large dose 100 mg metropil that caused ejection factor to plummet from 39 on Fri admittance to 16 (category 4) dangerous on Tues. Cardiologist on duty at that time thought I needed a heart transplant so got me an outpatient appointment at cardiac clinic Toronto General 1 week later. So stayed in NYGH extra week so monitored before being discharged on day of outpatient appointment at TGH. My husband drove me to TGH where I was in intensive care. Drugs given at NYGH were stopped. Started on very small doses of appropriate drugs as heart improved to ejection factor 22 at discharge. Now taking heart rehab at Scarborough Rouge Valley Centennial. Discussion on medical prescriptions [illegible] start very low doses and gradually increase. Since then I've heard of another patient with a virus attacking heart underwent same horrible experience 4 years ago at NYGH. Almost died!

 Opportunity for improvement: Have cardiologists at NYGH benefit from best practices at both TGH and SRVCH hospitals who have more experience/expertise in treating heart failure. I would not want this inappropriate care to happen to anyone else. Additional note regarding study: I went to Peter Munk Cardiac Clinic for aftercare and am still going there. It takes up to 1 year for the heart to recover after a viral infection. [illegible] I did not have any aftercare at NYGH services."
- 40. "The program was very good and made me feel very comfortable."
- 41. "I have had a lung flare up and am now on antibiotics and high doses of Prednisone. The healthcare provider was able to make a very timely appointment with the doctor for me. Thanks."
- 42. "I feel shocked because I feel very good, I've been in Canada for 25 years, I didn't spend a penny, and the follow-up program is very good. The nurse made phone calls to follow-up with me and I thought that that was very good. Al- in-all the program was very excellent."
- 43. "From the ladies and gentlemen at the info desk, the coffee servers, the ladies auxilary workers who rescued me when I zigged instead of zagged, the physio team, the doctors in emerg and nurses, everyone was exceptionally friendly and I received excellent care. Must not forget Dr. [Redacted_1] and [Redacted_2] and also x-ray technician whose name I don't know."
- 44. "I felt well cared for in hospital and the at home follow up was amazing."
- 45. "The care at NYGH was so superior to the experience at Major Mackenzie House."
- 46. "Interesting. I didn't realize what it was all about before speaking."
- 47. "The program is excellent. I was very impressed. My cardiologist is fantastic, the nurses were on time."
- 48. "A very good, impressive, comforting experience. Excellent personnel, doctors, nurses and others."
- 49. "I appreciate the positive and supportive efforts of the visiting nurse. Also the program as a whole was very supportive and gave me confidence to adjust to my health concerns in its initial stages."



50. "I really liked it. It was very good. I mean it was some days I couldn't go on the bike but I did as much as I could."

CW - H2H

- 1. "My hospital visit to emergency was not bad bit of a wait to be seen which was to be expected. It was a very long wait after taking the tests for the doctor to finally come over and tell me the results which only took literally less than a minute that was most frustrating. The home health care I received was excellent and I was most impressed. All the nurses were exceptional and they were able to take my schedule into account in arranging visits so I didn't miss any time off work. I was very impressed."
- 2. "It was wonderful. [I] had to have an IV, wasn't able to drive, had to have [the] bag changed every 4 hours. Prevented [me from] having to stay in the hospital where [I] often get asthma attacks due to the cleaning products. [I] highly recommend it. Girls were super nice, helped [me] with lifting as well."
- 3. "It's been really good, had no bad experiences except for having to find [my] own buggy to leave the hospital after [I] was discharged. Otherwise it was great."
- 4. "The waiting time in the emergency room is too long. The parking cost too much money for patients; it is unfair. It cost \$40 per day for patients who are receiving treatment."
- 5. "[The] program is excellent, a program supported by what we've paid over our lifetimes. [I] have been taken care of. Very satisfactory."
- 6. "It was a good, new experience."
- 7. "Was on IV for 10 days for infection, nurse came daily to replace medication, check blood pressure, temp., etc. Would be better if the same nurse came each time to my home. (Hospital to Home) program."
- 8. "The at home program was ok, the people that came were nice. The hospital staff are rude, mean, down right disgusting. Attitude from nurses is not right. No compassion."
- 9. "All is good. Thank you."
- 10. "Would really like if Ontario health care would get a vein finder/vein viewer, which are sold in the U.S. [I am] like a pincushion and can only get an IV in one arm due to edema in the other. [I don't] like the wait time for specialists, [I have] had to wait 6 months."
- 11. "The program was fine, [I] liked having CCAC come in, all the people were friendly. Sometimes they got the hours mixed up, [I] live in Shelburne and they were coming from the Mississauga office.

 Sometimes they did not come at the time they said they would. Other than that, everything was



fine. In hospital, the wait time in emergency was longer than necessary, but [I] understand that there were people who were in more severe need of care than [me]."

- 12. "It works!!! The nurses from CCAC are very thoughtful and caring."
- 13. "[I] had a great experience, the program is wonderful for patients who really don't need hospital-level care. I had to get an extension [of the program] requested by the dentist. [He] talked [me] through changing and resetting [the] pump. I received good self-care/management information. Once the extension was requested, the transition was smooth."
- 14. "I didn't get a room for 4 days was sleeping in the hall way."
- 15. "It was great and the nurses were very helpful. They took care of everything, and called 24 hours in advance to set an appointment so it was never rushed. It was a great experience, saved [me] a lot of time, and helped [me] recover better."
- 16. "Nothing wrong with the program. The only problem was between the first visit to hospital and seeing the specialist. The program was good; the people were great. The problem was with the hospital and not with the treatment."
- 17. "Yes. Overall my experience was positive. Here are my other concerns: 1. Wastage of medical supplies. I had a full medium box of stuff (medical supplies unused, unopened and in original packaging like IV Lines) could not be returned so I ended up donating them to an organization that donates to 3rd world countries. 2. Did not know that I had to accept supplies personally. 3. Nurses changed almost daily so you were at their mercy regarding scheduling so lots of waiting around. 4. Help available when it was needed after hours. 5. I would like to share 3 photos of excess medical supplies but I cannot figure out how to insert it in here so if you can share with me an email that I can send them to I would appreciate it."
- 18. [The patient indicated that she was misdiagnosed and given the wrong medication, which led to her readmission] "Some hospital staff are good but it only takes one staff member to ruin experience"
- 19. "[I] was pleased with the nurses that came to my home. They were very pleasant and helpful."
- 20. "We get the best in health service that we can in the Orangeville area, with what's available to us. Wish we had more choices of doctors."
- 21. "The program is good. The only thing is that it takes time for [me] to be checked for [my] illness. There are a lot of people in queue."
- 22. "The emergency at Etobicoke Hospital was extremely busy. The staff did the best they could under the circumstances."



- 23. "[I] was very happy with the service at the hospital and at home. [I] was happy with the nurse that came to change the IV. [I] was happy with everything except for the parking, which was too expensive and meant that [I] had to change physiotherapists so [I] didn't have to pay \$15/day for parking. [I]also have a long wait time for an appointment to get an MRI, and [I am] in a lot of pain."
- 24. "The home care provided was satisfactory. Post-home care there was absolutely no follow up. I am completely dependent for performing all my daily activities upon my family."
- 25. "I really appreciate the program so I'd give it an excellent."
- 26. "I feel some kind of reassurance that somebody cares, otherwise this survey wouldn't be done. That's a biggie, actually. I feel oftentimes our medical system is so overwhelmed that proper attention isn't always given. All-in-all I am grateful there is a system, I realize how fortunate we are."
- 27. "No, just because I can't remember. I have MCI [Mild Cognitive Impairment], it's a precursor to Alzheimer's."
- 28. "I was 100% satisfied with the care I got in the hospital and at my residence."
- 29. "1. Waiting time too much -> First for registration, then for tests -> Waiting for results -> Waiting for doctor. Overall waiting is too long. Waiting time must be minimum."
- 30. "Hospital 2 Home is a wonderful service. I hurt my leg and having the nurses come to the house and give me the care I needed instead of going to the hospital every day. The staff were wonderful at the hospital and at home Thank you so much to everyone."
- 31. "Additional Question suggestions: Did staff listen to your concerns? Where staff competent in the care given? Was the treatment effective and correct for the health issue? Was service and care prompt and timely? Did the community care pick up on any mistakes ordered in the hospital (i.e. wrong dosage)?"
- 32. "The nurses need far more training in hooking up IV as I had to make 2 trips to the hospital just to have the IV line changed after several attempt at home."
- 33. "The biggest issue is that service in emergency takes far, far too long. Always 6-7 or more hours this is unreasonable. More doctors and nurses should be provided to improve patient care. I as many others believe time is a very important part of good care."
- 34. "Sometimes telephone communications were not good. A couple of times Medical Referrals were not received from the wound clinic to CCAC (Fax) e.g. continuation of antibiotics, change in wound dressing techniques. When the machines malfunctioned, it was very distressing, IV pump, Vac machine especially at night. Phone calls were not answered or returned during the night (after hours). One IV pump was not calibrated properly air in IV tube. One Vac machine was defective -



alarms kept going off. So being at home without near at hand nursing care was anxiety producing. The Hospital 2 Home nurses were excellent."

- 35. "Program was excellent, thank you."
- 36. "They're not adjusting the psychological part of it. The physical part is being looked at. Proper explanations are not given for why treatments are being given. The doctor doesn't take the time to say "well this is for this". I think they should spend more time teaching people how to do prevention and how to eat properly. Nothing is being done about that. They're pushing medication more than anything and not addressing lifestyle issues. And the mental part of it... they're treating people like they're just a body and not a mind. Psychological issues like fear they don't address."
- 37. "I think it's well looked after, well done by yourself and other people asking to find out how things were done at the hospital. I'd also recommend that hospital [Etobicoke General] to any one else because I had very good service when I was in."
- 38. "Excellent service."
- 39. "The 'community health care program' is a good support program. The nurses have enough experience to perform their duties. However, I do think that hospital staff are not really interested in CCAC and vice-versa. From a patient's perspective: i) A patient does not view or really think about the hospital and CCAC as two different institutions. For a patient, they both are the same. ii) A patient is only concerned about the 'treatment' an not about the role. iii) A patient does not differentiate between a 'nurse' who works in a hospital and a 'CCAC nurse.' A nurse is a nurse. We expect the same level of service from both groups of nurses. iv) In this day and age, why do we have to go through a GP to meet a specialist. It is a total waste of time. v) Both my GP and specialist would not do the procedure. I was pushed back and forth like a ping pong ball. vi) It was my decision to go to the 'emerge'... and after waiting for 8-12 hours I was told that this procedure could have been done by the specialist... vicious circle. *A lot of equipment goes waste as the pharmacy does not take them back (contamination reasons). Bandages etc. should be dispensed as much as needed and not more or less. Does an audit/inventory take place to monitor the dispensation of bandages, syringes, etc.?"
- 40. "Fair."
- 41. "I spent 5 days in isolation. There wasn't enough staff. The portable toilets weren't emptied enough and many times found myself sitting in my own urine, rang the buzzer, they were too busy to answer. Other than that the nurses were very kind and helpful, there just wasn't enough of them."
- 42. "It's ok, everything."
- 43. "Good."



- 44. "We need to fix things fast. There is lack of communication amongst your professionals, need to invest in system that allows communications among your medical professionals. When selecting workforce personnel ensure that there in it for the right reasons. I encourage to have (for all med professionals) that they all have to go through a program in dealing in people. There is lack of empathy from the people that have been hired. Revamp the way our mental health system is handling. GP, psychologist, psychiatrist, they all need to get along. Because of the disconnect (between them) we the people are being impacted. So please let's all play nice in the sandbox and collaborate. Because being a medical professional is to care for the patients. I'm going to be changing my career as a result of this. I've been a Ping-Pong ball."
- 45. "The hospital stay was a bit long but thorough. The home care was very good, prompt, with communication regarding appointments and medication. The pharmacy (CALEA) was also excellent providing delivery and pick up times."
- 46. "I am happy with services & outcome."
- 47. [Caregiver Comments] It was great to have my Dad be taken care of at home, this lessened his anxiety and nervousness to stay in the hospital.
- 48. "Hospital stay exceeded my expectations and for me was excellent. Homecare was most convenient as well as providing me with ongoing excellent care and education regarding my condition and treatment."
- 49. "The only issue I had was with the consistency of the visits, I had to wait, resulting in me not getting to work some days or going in very late. Either way I am able to work from home so it wasn't to big of a deal but if you say you'll be there at 10 am then showing up at 12 or 1 pm makes it difficult to plan my day."
- 50. "Just that in the hospital, I was really faced with decisions, but the doctors were there to guide me to make the right decisions, when I got home I didn't know what home care was all about. I'm so glad for this blended program, I really like the way they combined both programs, hospital and home. It was really convenient with the way they have been linked together."
- 51. "Both hospitals do not share info some nurses exceptional, some incredibly lazy & not patient centred."
- 52. [Caregivers Comments] "When my Dad was sent home, CCAC set up a nurse to come daily for IV medication. Confusion between hospital and CCAC whether he got his first dosage at hospital or at home. Had to leave work to take him to walk in -- which was told by a CCAC representative I had to do in order to get his first dosage. But was mistaken as they were going to send someone to his home for his first dosage."
- 53. "Discharged too soon prior to the [illegible] healed. Now have to transport myself to out of town clinic for continued treatment."



- 54. "Thanks to Ministry & Community they are doing their jobs with heart helping & looking after the patients with kind heart & loving care. I appreciate it with all my heart. Thank you."
- 55. "Excellent program. The "Hospital 2 Home" program has been of great benefit to me as twice I required IV antibiotic treatment as advised by Dr. [name redacted] at Mount Sinai Hospital in Toronto. Both times, I went to the urgent care [Hospital Redacted] and the care & treatment & establishing home care for IV was carried out in a very timely way and I am grateful for this. / Q42 comment: Thanks to the IV treatment for the infection, I was able to help my mother through Palliative Home Program."
- 56. "It's an excellent program."
- 57. "Dear Sir, I like to share my experience at Brampton Civic Hospital. On [Date Redacted 1], I had a biopsy at Princess Margaret Hospital for prostate. This appointment was booked by Dr. [redacted] (urologist) at Brampton Civic Hospital. I was advised by Dr. [redacted_1] that using the MRI file the biopsy procedure can only be done at Princess Margaret Hospital. I just followed what Dr. [redacted_1] advised me to do. This biopsy procedure was done by Dr. [redacted_2] and he gave me the patient instruction, what to do if I develop infection. I started to have chills, fever, shivering and feeling very weak, I went to Brampton Civic Hospital on Saturday [Date Redacted_2]. I handed the copy of the letter Dr. [redacted 2] gave me at the Princess Margaret Hospital to the triage nurse. Please note instructions were not followed at the emergency dept at Brampton Civic. After blood test I was given the antibiotic (see attached copy) I was discharged. [Date Redacted 2] Saturday night I started to have the fever and chills and I could not control myself, my wife took me to the emergency dept at Brampton Civic Hospital again, handed the letter from Dr. [redacted 2] to the nurse at the registration desk. I was on the stretcher all night and was given the antibiotic and Tylenol for fever. Sunday morning Dr. [redacted 3] came to see me and said that he is discharging me (10:30 am). He asked us why the procedure was not done at Brampton Civic Hospital, me and my wife explain to him that we don't know but it was Dr. [redacted 1] who booked the biopsy at Princess Margaret Hospital. Dr. [redacted 3] said to us that he is not going to have the urologist see me because the procedure was not done at Brampton Civic Hospital. That I have to go back to Princess Margaret Hospital. He would not listen to us and at one point Dr. [redacted 3] said that Dr. [redacted 1] is a good friend of his and my wife replied that if Dr. [redacted_1] is your good friend then ask him why he sent us to Princess Margaret for biopsy procedure, he just left and the nurse with him was very rude. Wife ask the nurse that she wants to talk to the doctor but she would not listen and keep saying you heard what the doctor said. I was discharged with the prescription for cypro 500 mg even though Dr. [redacted_2] suggested to give ertapenem. Sunday night at 9 pm my wife called the ambulance because I was having high fever, chills and severe shivering. Stayed on stretcher in emergency all night still was not given the ertapanem, CT scan ordered, I spoke with doctor at the emergency and explain my situation that this is my 3rd time I came to hospital and I am not being looked after, explain the Dr. [redacted_3] situation and this doctor said that [patient] is not going home until all procedure are done. As luck has it on Monday morning I think it was between 8 am to 8:30 am my wife saw Dr. [redacted 1] and grabbed him and explain to him what we been through especially my experience with Dr. [redacted_3]. I even mentioned regarding the letter from Dr. [redacted_2] to Dr. [redacted_1]. So



by 10 am Monday things starts to get into action I was lucky enough to see Dr. [redacted_1] otherwise I don't know what would have happened to me. I am a senior citizen and I shouldn't have to go through this horrific experience. I just wanted to bring to your attention nobody should have to go through especially a senior citizen. I am attaching copies of the reports that I have with me that were given at the hospital. Thank you for listening to me and I hope that some action can be taken and improve the service by the hospital board."

- 58. "The only complaint I have is the Doctor at the hospital. As I was in a lot of pain that day and he insisted to cut finger as I was in pain + I asked to be frozen and he said that I don't need to be frozen. I would have to disagree with the doctor, he should listen to the patient more often!!!!"
- 59. Great treatment by staff, very caring & professional.

CTC-OCOT

- 1. "I saw no sign of a "one health team" or whatever it is called during and after my stay."
- 2. [Caregiver's comments] 1) "The "One Client One Team" wasn't fully explained she only was informed that she was being enrolled into a program. The speech therapist from Providence was the one to tell her that she is lucky to get into the program very quickly. Extremely benefitted from the program. Getting rehab right away helped her recover very well. 2) She was a bit disappointed to stop receiving care right when the time period ended because she didn't realize that there was a pre-defined time period this was not explained to her. She felt that she needed more rehab when the program had ended for her but did not receive it and has not yet fully recovered. She was offered other options to join community-based programs which helped her understand her illness.
 3) People at providence were fabulous good team. Sunnybrook provided unbelievable care. 4) Parking costs were outrageous added up definitely. At the time of hospitalization and being discharged, she never thought about the months of parking costs that would add up. She encountered difficulty and more out-of-pocket costs were incurred when no caregiver was able to provide assistance with transportation, which then she had to take Ubers or taxis."
- 3. "[I] have many health problems, none severe, but all put [me] at risk and [I] has been in the emergency room many times. As a patient, [I] feel that there is expertise, and [I] was usually well looked after during any of the incidences, and yet no one seems to put it together. Because of [my] palpitations, [I] was sent to various experts who referred to other specialists. No one put it together. [I] had numerous tests. [My] family doctor still can't give a differential diagnosis, there seems to be, from [my] point of view, no person [I] can go to who can tell [me] definitively what needs to be done. [I] feel shuffled from one expert to another. Each expert deals with it in their own way and in their own realm. [I] find it disconcerting. There is a predisposition with many doctors to say "maybe it's anxiety." Anxiety seems to be the catch-all. [I] had attended a mindfulness group, but the anxiety is not the cause. There is pain, stomach problems, etc. [I] find this disconcerting as well; [I] have dealt with and lessened [my] anxiety since the stroke but [I] do not feel that this was the cause. [I] refused anti-depressants."



- 4. "One thing that I was not impressed with is the nursing care. I had a stroke, I was unable to walk. Nobody came to me to ask if I needed to go to washroom and if I needed to brush my teeth. My daughter came and took me to the washroom so that I could brush my teeth. Because I had a stroke, there was no salt and sweetener in the food. The food was lousy."
- 5. "It was very good. They referred [me] to Providence for physical and occupational therapy. It was excellent care, I received very good care wherever I was."
- 6. "Everything was good. [I] was very happy with the services received. The health care team was amazing and very helpful."
- 7. "When [I] left the hospital [I] was recommended by the occupational therapist to attend physiotherapy, and thought it was excellent. [I] had improvement in muscle development, particularly on [my] left side. [I] was warned that numbness in [my] left hand and [my] balance would probably not improve, and this has been true. [I] walk with a cane but do not use it outside. [I] had a problem with night staff at the hospital. Usually no doctors were available, the problems [I] had were not major problems, for example if [I] had a headache there was no doctor available to give medication. [I] also fell in the washroom and no one was there to help."
- 8. [Caregiver's comments] "I did this survey for my father. My father does not read or write in English. This was a great issue while he was in the hospital. There was no communication of this language factor. He can respond but he does not know what he is responding to. We had to always ask and remind about the literacy issue."
- 9. "Because of past experience, [I] was really pleased with how [I] was looked after and handled at the hospital, surprisingly well."
- 10. "Not sure exactly which part is the 'program'. Is the entire health care that I received considered to be part of the program?"
- 11. "The program is ok. Anything concerning the government of Canada is ok. They do what the government tells them to do. It's a good country. God bless them. God bless Canada."
- 12. "Other than a medical appointment, there was no Sunnybrook follow-up and I think there was supposed to be."
- 13. I was not even aware or told that I was in this "Integrated Care" program. Also I am a resident of British Columbia, thus no OHIP. Overall, the care has been very good.
- 14. "The doctors were terrific, but the nurses in ER were understaffed and therefore too stressed to care. I had bruises from the way they put on the IV, they were in such a hurry. And the nurses in stroke were good. [The neurologist] was very accurate in diagnosis and treatment. There were times I was left in the hospital hall by myself and I felt very anxious. The nurses would say they'd be back in 5 minutes, and they'd take 30 minutes and I would get anxious and pee myself. But I'm very thankful to be alive and I thank the Sunnybrook staff."



- 15. "When you can't get an answer to what is a very, very severe head problem, one tends to look at the health care system and say surely somebody can tell me something, can't you. I'd love somebody to sit down and tell me that they can find a method of finding what's wrong in my head. It would be nice if someone would tell me that I can't do an MRI, but we can do this. I'm not going to find out if I have a serious problem in head or not."
- 16. "Nursing was not always available."
- 17. "Excellent. NYGH staff are outstanding."
- 18. "Perfect ideas."
- 19. "Complete details regarding my medical conditions and steps on what to do to be back to my normal life. I wanted to be in good health."
- 20. "I don't think that hospital care should not be available on weekends. I arrived at NYGH on a Saturday. I was given no food, drink, medication, treatment or room until the following Monday. I was totally sleep deprived in emergency as well. I was in hospital due to a stroke and I am convinced I had many more strokes during my time in emergency, as, in emergency, I developed double vision and dementia. Eventually I was diagnosed with multi-focal bi-lateral ischemic strokes. I was put in a semi-private room with a male patient outside the door who was loud and noisy and who took the door of the room apart. On the other side of the doorway there was a lady who called for either "Ma" or "Operator" incessantly. I was terrified. I was transferred to a second room with a lady who snored so loudly I continued to experience sleep deprivation. When I was taken down to have an MRI I was so sleep deprived I could not stay awake and did not know what was happening to me and messed up, not completing the MRI. The second time I went down for an MRI I was sedated but not supervised and I ended up collapsed on the floor twice. If this is the "new integrated pathway" you can keep it. My family and I were disgusted with the lack of care. Coming back to lack of treatment on weekends, if airports can operate 24/7, I don't understand why hospital services, which are far more vital than transportation services, can't operate on weekends like they do on weekdays. In my case I ended up with far more serious problems than I would otherwise have had if I had had my initial stroke on say a Monday."
- 21. "One thing that really irritated my wife, when we were at St. John's I had to be released by a certain date no matter what condition I was in. There were options other than home, like an old age home, but I said no way I'm not going to an old age home. The part that bothers me, once you get to 90 days, that's it, there's no more. It doesn't go by what shape you're in. I don't know what difference 90 days is going to make. I'm incapable of taking care of myself. My wife can't keep taking time of work. Then the bills would be extremely hard to pay. The PSWs shouldn't go by time, it should go by how much better you are. At this point in time I can't walk, and they don't care, it's still done at 90 days. The nurses were all wonderful, they were really overworked in a lot of cases. 1-2 nurses tried to take care of 5-6 people, which is impossible when 5-6 want showers, to be fed before you have to be ready for physio and occupational therapy. "



- 22. [Original comment from mail version] "I was not in program." [Called to clarify] "I only went back once, they said that was all they could do for me. They didn't determine whether it was a stroke or [other condition]. They gave me some papers and said they would call in a month. They didn't call, so I called them and they set me up with an appointment with the doctor, but that was it. They didn't direct me anywhere else."
- 23. "I had good help."
- 24. [Caregiver's comments Part 1, taken over the phone]: "We've been told, and I believe we give my mom really good care, so I felt comfortable when she initially got sick that we could take care of her. I didn't really look at the binder that much because I felt I might have known what to do. There was a lady next to my mom and she really looked vulnerable and her son didn't seem highly engaged in her care. Nobody sat with me with the binder, they handed it to me. It was my decision to look at the binder or not. The other patient was talking to us and I think she could see that my mom had a different level of family support than she did. I realize the binder is really quite good support, if there was a nurse or social worker who could sit with the family to go over the binder, if there was someone who could assess, present the binder in a way and guide someone to really use it according to their needs that would be great. My main concern for my mom was to keep her safe; it was to prevent the secondary concerns. We put her in transitional care for 3 days after the hospital so she would be monitored during the night. Somebody might not be aware of the struggle to get more services involved. In the end with more services they have a better quality of life as a caregiver and the patient will have a better quality of life. The binder was a great way to amalgamate a lot of resources, but it was just handed to me. In my case, I didn't look at it right away and I knew what to do, but people who aren't connected to supports in the community, might need more, whether anybody evaluates the caregiver's needs, capacity. It is a great resource, and people are so overwhelmed. My mom, when she got out, she moved up in a couple days, then went down after it got cold. I'm the one who pushes everything to make sure that her attitude is good and she gets all of the services she needs. It was only pushing through to the point where I was exhausted that we got her in the occupational therapy. She's definitely more tired, but her interest in hobbies is back to where it was." [Caregiver's comments - Part 2, written on mail version] "My mother has strong and caring family advocates which help to ensure a positive experience. If she did not have this support her experience may have been different because she could not express her needs and goals."
- 25. "A good wake up call to better take care of myself, to rest more, diet and get good workouts or exercise."
- 26. "In general, I am satisfied."
- 27. "I thought I received excellent service from the health care system from start to finish. You often hear complaints about the health care system, but after going through this emergency situation we went immediately to the hospital after my wife discovered I'd had a stroke they dealt with us very quickly, and as a result of their excellent service they administered TPA, my major problem at



- the outset was speech, all of a sudden I could barely talk. This TPA brought back most of my speech. For the most part it was just phenomenal."
- 28. "Everyone involved with my treatment and care was caring and helpful at all times. I never had any cause or concern about the treatment or care I was receiving. Thanks everyone!"
- 29. "Inpatient and outpatient therapies thru UHN has been fantastic. You are treated as an individual and not a number and they are truly concerned about your recovery, health and well-being."
- 30. "The food was poor at St. John's, some unacceptable and left on tray."
- 31. "Very impressed with the follow up program at St. Johns Rehab Center. Also how professional all the staff was in my dealings with them."
- 32. "Program is great, however more information would be informative once leaving hospital, as to more side effects that may show up later. Thank you."
- 33. "St. John's Rehab too long and no rest time too intense. No merit."
- 34. "Very good program. People are really nice and make you confident. At Sunnybrook I wanted to go the bathroom, the door was very heavy, the nurses were not paying attention and I fell down and got a stroke. Very bad experience. Food is also very lousy but that wasn't my concern."
- 35. "My stroke was very mild, therefore, my recovery was a very smooth, and fast."
- 36. [Caregivers Comment] "The team at Sunnybrook were excellent!! They treated my 98-year-old aunt with care & compassion & we are all very grateful!! Thank you!!"
- 37. "The program is great. Good program, I like people to keep up to date with what is happening with me, that's great."
- 38. "Had excellent during all facets of recovery."
- 39. "My usual activities are not changed except that my driver licence is still suspended in spite of Dr [Name Removed] contrary recommendation to the Ontario ministry."
- 40. "The neuro team at Sunnybrook was thorough, engaged with me & my family, responded quickly & always explained themselves or the test."
- 41. "I went for 3 months twice a year to St. John...[indistinguishable]. I live close with 1 hour help everyday."
- 42. "We were really happy with the care, the way they treated her, we can compare to other hospitals and back home country. She was really happy with the treatment she got. they were really happy. This was the opposite experience with Mackenzie hospital. We were terrified and sitting at home



with her worried about what would happen to her. Much different story with north York general hospital."

- 43. "I think they have done a wonderful job."
- 44. "It was ok, my therapy and all of that they were very ok. I am satisfied."
- 45. "North York is a very good hospital; they are extremely good with their services. North York provided excellent care, and they did their best, and I have thorough gratitude to the institution."
- 46. "I was very impressed with the program overall. I do wonder though, since I am a nurse, if some things were assumed. I, for example, never had a discussion with anyone regarding diet changes, even though my BP and cholesterol levels were high. It might help to remember that health care professionals specialize, and may not have all the information needed. Also, when we become patients, a lot of critical thinking and knowledge go out the window. We're just as scared as a lay person, and may need a little emotional support too. It's hard to be the patient."
- 47. "It took the night nurse 30 minutes to answer the bell. There is a need for more nurses."
- 48. "No complaints. Nurses were very nice, very helpful. Considering my condition, it was a very good experience with the hospital. Very, very satisfied with my care."
- 49. "Very hard to go to appointments as I have no relatives or friends available to drive me."
- 50. "They told me I wouldn't even make it. I can't thank them enough."
- 51. "I'm thankful and appreciate the care I received at Sunnybrook Hospital."
- 52. "The rehab was fantastic, and the girls were fantastic. The nurses at the hospital were great."

MH - PPATH

- 1. "I thought it was great, it did relieve us a few times with my blood pressure and that kind of thing. I thought it was very good, very comforting to know. I had some bleeding and they came out to look at it, it eased my mind. I thought it was fabulous."
- 2. "I think the program is outstanding, it's collectively... it's like having a whole bunch of real life heroes on your team. People that really give a shit, and I don't know why they do, they're just special people. I was just treated so good by everybody, everybody was just amazing. Especially the nurses. The nurses, to me, what they do is just incredible. This was my first time in the hospital, and I couldn't get over it. Plus, for me it was an unreal experience right from the time I went in the hospital, when I first went into short stay, by the time I got into my room. I had nurses from the short stay on a Saturday when they weren't working coming to visit me. I never expected that. My surgeon is world-renowned, larger than life, he comes in to meet me and I'm in awe and he's such



a good guy. He's a life saver for a living. It's amazing, it's just amazing. It was the greatest experience under the circumstances. I had a good attitude, I didn't bother anybody, I went in there trying to help and do what I could. I couldn't have asked for a better experience. Just an amazing group of people."

- 3. "Well, I guess if they want to work a program like this and they want to track it, they should probably have more contact with the patient. If that was up to me, then I guess I didn't perform. I just looked after myself."
- 4. "It's a very good program, the health care is very good. I don't have the transport to get to rehab, the hospital what should I do?"
- 5. "I feel satisfied with the program."
- 6. "The program works very good, to a certain extent. I would say it is very good, not excellent. From the time I was admitted to Trillium to the time I got my surgery, it took quite a long time. That was one of the major flaws. Other than that everything was good."
- 7. "I think it's well done, well-organized, with competent people. I have nothing but good things to say about it."
- 8. "The program was ok. No, so far that is the case, one thing, I don't get nothing from nobody, just my wife helped me, and my daughter but she's a special lady, she has to help me out too. I have to get somebody to go to the bank for me because I can't drive."
- 9. "Well, there's something going on wrong with the program because I did not have a good experience at all. When I was at the hospital, my daughter lives 5 hours away and she had to ask if I was going to get help everyday from nurses, and that didn't happen. It took them 4 days for the first visit after I left the hospital. After that I got infected and I went to the emergency department and had to run around to get some help. My daughter had phoned a number for me because I was getting upset and I didn't want to get upset, and she tried to get some information and help for me, and that was a real joke. It took me to be upset at them for them to come and see me and get infected where my incision was to start providing the help that I needed. The nurses were very nice, very professional and all that, but they don't have good communication with their... the person that gets their appointments all set up, they were always a day late, they were supposed to come 3x a week, and on the weekend they never showed up, sometimes it was Friday, Saturday, Sunday until I saw somebody. That's when I think the infection started. I had to be rude a bit to finally get them to smarten up. When they came to see me it was okay, but they didn't come too often, not as often as they were supposed to. Somebody didn't do their job right, and it's not the front line workers."
- 10. "It was pretty good."
- 11. "It is not a helpful program, it should improve, it is a good program, but it needs a lot of improvement. The follow up should be there, one call is not enough, it should be extended to a



- couple months. A person who has undergone a bypass surgery is not a 4-week job. This program should correlate with other agencies to put them properly back into life."
- 12. "I think it's a good idea, innovative, and it should result in cost savings and it should benefit those patients in particular who have other medical conditions, who have gone through surgery, and who may or may not have support from family and friends. For those who are older than I am have difficulty as a matter of course. The benefit of not having to call 911 and sit in emergency and wait 8-9 hours before being treated is a great improvement and hopefully will provide savings to the tax payer."
- 13. "Work on ways for patients to really understand their recovery for such a short hospital stay after surgery."
- 14. "It has dramatically affected my sex life, nobody will give me any information about drugs and side effects, nobody will tell me if it's odd, permanent, how long it will last. Nobody wants to touch that."
- 15. "Hospital not being clean properly unsupervised untrained cleaners."
- 16. "I can only say that I was very, very pleased with the whole service itself. It's a difficult, and certainly at times confusing, situation having major surgery, but the patience and the understanding of a lot of people in the program, they do go and help out certainly beyond what most people would think is standard. I was very pleased with everyone that helped with the process."
- 17. "The services I received at Miss. Hosp. [Mississauga Hospital] were excellent. Nurses and other staff were there to help in any way after 6 weeks in hospital. Excellent."
- 18. "Staff in general are excellent in Trillium. A few staff needs to understand the sensitiveness of pain one person is going through they talk as if it is not a big deal on one occasion I asked a nurse (this is only one) ask for pain medication as it was unbearable she said she will come in 5 minutes but came after 1 hour."
- 19. "Recommend having more in-person support after surgery. A nurse visited once and that was very helpful. Felt a few more visits could have alleviated some of my concerns."
- 20. "The program is O.K. Thank you."
- 21. [Original Comment] "There was some vagueness on somebody giving me a shower (from St. Elizabeth)." [Called to clarify difficult to read] "Somebody was going to come to give me a shower. They called late one night but that wasn't convenient so they said they would call next day and they never did. My granddaughter helped me. It wasn't scheduled or organized very well."



- 22. "Need information about medications I am going to take home after leaving hospital. It would be better if hospital setting up the cardiology appointment. I have to call surgeon office to send referral to cardiologist before I can set up an appointment."
- 23. "I found home care not too interested in making a second visit, when asked they wanted to direct me to my family doctor so I did not bother them."
- 24. [Caregiver's Comments]"Yes she need more help at home her personal [illegible] bathing 3 times a week, physio 3 times a week."
- 25. "Spectacular heath care for me. I moved to Ontario from Quebec and I found the health care in Ontario or at Trillium particularly amazing. In Quebec I found many issues but none here."
- 26. "It's an excellent program. I never had problems, I needed them 2-3 times to come to my home and they were very prompt. The healthcare givers were very knowledgeable and helpful."
- 27. [Caregiver's Comments] "1. The St. Elizabeth visitor was excellent and very much appreciated. 2. Follow-up visit within 3-weeks after leaving hospital, with St. Elizabeth's, would have been appreciated."
- 28. "Approximately 2.5 weeks into my recovery an annoying dry cough kept me from talking! I called the PPATH Coordinator who, in turn, contacted the pharmacist and e-mailed the surgeon. Within 2 hours she relayed responses from both to my satisfaction."
- 29. "I believe that Canadian Health Care is of a high standard and we are fortunate to have what we have. I am thankful for this blessing of the Lord."
- 30. "I have never been in a hospital aside from having babies, and I was very impressed with the overall care and attention to all my medical needs. Thank you."
- 31. "I thought the program was excellent. It was top-dog for me. I checked it out, it has an excellent reputation, and they did everything they said they would. I was very impressed with the cardiac protocol; they kept the pain under control and everything was well paced. I was really, really impressed by it. I was healthy otherwise, this is the only surgery I've ever had. Everybody worked together. My dad had the same surgery at TGH and there was no comparison they gave me much more information. I came out feeling very confident. I was so impressed I'd be your poster girl for this. If I was in the States I'd have been bankrupt. I'm so glad I'm Canadian."
- 32. "It is very helpful."
- 33. "I've been looked after, I've been good, had no problems."
- 34. "Never saw the doctor during the hospital stay."



- 35. "Post-surgery hospital stay (5 days) requires changes to food given. The patient is not able to eat such food at that time. Home-cooked food is an option but it must be advised early on. Chicken soup and the like are palatable too."
- 36. "PPATH is exceptional. Don't know how we would have done the recovery process. Ended up with incision infection. This program made it possible to stay home and calmed the anxiety associated with major surgery. Excellent Plus!"
- 37. "Super hospital, and staff!"
- 38. "The program philosophy and goals are excellent. In my case it took 3 weeks to get a response from Cardiac Rehab Program who promised a letter re: rehab program 3 weeks ago still nothing. As well, I called the hospital number and no one returned call for about a week (Christmas?)."
- 39. "This is a good idea. Keeps people out of Emerg. or Dr.'s office. I did not like the nurse I had as she was abrupt, hard to understand, and called me a name I did not like, "Miss [Given Name]" instead of Mrs. _____ which I had asked her to use. As a result, I did not call a second time when I had a problem. I went to my G.P. Hospital Stay: The head nurse tore bandages off and took a piece of skin 1.5"x0.5" off my neck. She did not comment. The nurse practitioner saw this the next day, said it was starting to "bubble" and dressed it with ointment and artificial skin to aid healing. Still pink. Terrible food!"
- 40. "Very important: having a heart attack takes way too long in waiting room. 8hrs to see doctor. Crazy. We all say these things I am sure no one does nothing. Still nauseous & upset stomach."
- 41. "Well done helped me greatly thanks."
- 42. "Everything was good, the hospital was good, I really don't have any complaints."
- 43. "Not that a bypass experience is great but all the doctors, surgeons, nurses, therapists etc. were awesome. Everyone knew their jobs & treated you with respect and made you feel everything was and is going to be okay moving forward. Can't thank them enough for this second chance. Thank you everyone!!!"
- 44. "Waste of money for the food that is provided. Most patients do not eat the food served to them. It is awful."
- 45. [Caregiver's Comments] The service my father received was amazing, from the procedure itself as well as the surgeon himself, was amazing, staff, nurses were great relaying to our family what was going on during/after the surgery. Felt safe and comfortable at the hospital. Thank you!!
- 46. "Program very helpful in my recovery. Very good experience. Cardiologist appointment not within the six-week period (3.5 months)."



- 47. "As a retired R.N. of 75 yrs old, I have experienced a lot of medical/surgical care over the years. My in-hospital care was professional and caring at all times. The staff carried out teaching and prep. for discharge continuously. The various members of the team seemed to be in communication and passed along any new or important info. needed both to myself and to family members. They helped make what could have been a terrifying experience into nine days of learning thank you."
- 48. "Overall I thought that my hospital care was very timely, appropriate and generally excellent with good results. It has been 10 weeks since my quadruple bypass. I have been for cardiac rehab stress test, and I am scheduled for an intake meeting at [Hospital and Date Removed]. I am not sure if there was some delay in starting this program in my local area (Halton) or if this amount of recovery time is expected prior to starting a cardiac rehab program. I am sure the program will be very good once I get started. In the mean time I have resorted to doing a lot of self learning etc., with regard to diet, cholesterol levels, the medications I am on and the side effects concentrations, exercise, mental state etc. Planning to be back to my full time work week of [Month removed]."
- 49. "I was in 3 hospitals, and everyone that worked there, they where all amazing if I had to rate it would be 10 out of 10 very caring people."
- 50. "I can't say anything more except that I am very thankful that we have this program. I hope this program go on and on for the benefit of everyone."
- 51. "I am very pleased with my experience I had with the doctors and nurses. I am impressed. Thank you."
- 52. "Impressed with all."
- 53. "Currently the care I've received has been exceptional. However, I can't comment on rehab as I have not yet started the program."
- 54. "Cardiac Rehab start date [April] for stress test. Actual start [May] My surgery was [Feb]. I think this is far too long to wait."
- 55. "Care received during hospital stay was second to none! Great healthcare system."
- 56. "Very helpful program. The duration must be 3 months & there should be a doctor also talking directly to discharged patient about any concerns & problems."
- 57. "Everything is fine. It was good for me."
- 58. "Hospitalization was to repair a heart valve, therefore, little conversation was held regarding lifestyle."
- 59. "Very satisfied with service from start to finish!!"



- 60. "Everything during my care was great to excellent except in my actual hospital room that was too noisy at night and some minor confusion in the mind of my family doctor relative to the responsibilities of my cardiologist."
- 61. "With Trillium and St Elizabeth, the afterwards was excellent, it was an excellent program overall."
- 62. "My experience at Trillium was Excellent. Left me feeling blessed to have been cared by everyone from The Cardiologists down to the nurses 'impeccable' care assistants. Everyone on the Floor 2 and 3 of Coronary Care in [Wing Letter] Wing. Words cannot express my feeling of Gratitude at the amazing care and compassion of All Staff members at Trillium."
- 63. [Caregivers Comments] My husband has had numerous surgeries over the years and this one was our best experience by far. The support and care offered and received was outstanding. Thank you!
- 64. "I am very thankful for the services I received during my stay at Trillium Hospital and for next one month after my discharge from the hospital. The staff at Trillium was very polite and always ready to assist. Putting Patient at Heart program was very useful. It was a big relief to know that someone is always (24x7) available. The nurses who visited us were knowledgeable. They provided useful information. Lots of thanks."
- 65. "Very reassuring to be able to check medications without doctor's appointment esp. as not able to drive for 6wks. Wish there had been more warning about breast discomfort and enlargement prior to leaving hospital. Great program. Feeder hospitals need to implement exercise program prior to sending patient on would make your rehab program better."
- 66. "Excellent treatment and care by all on the Trillium Hospital ward (Thank you)."
- 67. "PPATH program provided excellent information. Explained program, answered questions and the home follow-up was timely and an excellent resource."
- 68. "They are really good at the trillium, probably give them a 98/100, the food was really good. When they send people home they should do CT scans when they are discharged from the hospital, they should do the 100% any person who has bypass they should do that, sounds like a great idea, when they go home they could have a blood clot right there and the doctors and nurses don't know. The thing about that blood clot, they might think that its a surgery problem and they are weak and should go home, they should do the x-ray just to make sure on the hospitals part because nobody knows what is going on inside. All-in-all the hospital was really good."
- 69. "One follow-up visit by the Saint Elizabeth Nurse was not enough. At least twice over a couple or three weeks would be more reassuring. First visit too much time spent on administration stuff.

 "NOTE": I started to faint while the nurse visited me she did not seem concerned or suggest a solution, still concerned with getting paperwork done first. I needed a nurse at that point needed reassurance."



- 70. "Though having this operation stressed me out a lot, because of the help of my family & health care providers everything went well."
- 71. "We did not receive diet & lifestyle info @ hospital as program was not run on a holiday Monday (July 3) and we left before the next mth on a Thursday."
- 72. "The whole Trillium team could not have done more for me. From Dr's, nurses, physio, volunteers. I have nothing but good to say."
- 73. "All staff @ Trillium Hospital were wonderful."
- 74. "The entire process was exceptionally well done. Well explained. Excellent tests and information. Expert explanations and follow up. The medical people could not have been better!"
- 75. "The services provided by doctor, nurses, hospital staff & care givers were excellent & professional. Truly felt the warmth in their care. Kudos to all - God bless!!"
- 76. "The nursing staff, doctors were professional responsive, dependable & empathetic for the most part. There was only one nurse at Trillium on the first day I was brought there did not put the line properly and left me in pain throughout the night. She was in a hurry to go home."
- 77. "On many occasions had to call Nurse Practitioner to remind them that they have to come and change my dressing."
- 78. "All the staff and doctors and the other members of the hospital were very good and friendly. I really appreciate it and thankful to all of them."
- 79. "I think it's a good program."
- 80. "Overall, I thought my care that involved many people was outstanding. The cardio floors staff. Surgeons etc. was a very positive experience relative to the triple bi-pass surgery I faced. The PPATH program was also excellent and myself and family are very grateful for all the support & care at the Trillium hospital."
- 81. "The worst part of my care was the wait for surgery. For heart surgery, there is no acceptable wait period [illegible] above the 30-60 days [illegible]. I waited 46 days for my surgery. The stress and toll it took on my health and family is immeasurable. Improve wait times!!!"
- 82. "Good luck on this wonderful program!"
- 83. "When patient discharge medication and how to take them I went through lots of problem with Shoppers Drug Mart. every prescription fee and 5\$ plus blister package again charged me biweekly and 5\$ each. I have hard time with my medication."
- 84. "1 phone call made for information! Never returned call."



- 85. "Great program. Thanks PPATH!"
- 86. "After discharge from the hospital, nurse visit should be more not just after 2 days. Nurse practitioner that visits the patient should follow up with them."
- 87. "Nice if surgery arrived so deadline could be met. Q 27. My wife made sure of everything as I only saw the nurse my 1st month and that was for an hour."
- 88. "I appreciate the help of my personal care worker [name redacted]."
- 89. "Program made me feel very comfortable about my recovery future."
- 90. "After coming home from the hospital, a couple of days after I blacked out. Was taken by ambulance to the emergency. I had to wait 8.5 hours on a stretcher before I was put in a room and seen by a nurse. I had major surgery to my heart and was discharged with fluid in my lungs."
- 91. "I appreciate the program as it provided support for me as a patient during my hospital stay and after discharge when I was home."
- 92. "The hospital experience and service was excellent. All nursing staff was fantastic. Post care is mostly left to patient."
- 93. "Hospital is very noisy. Very hard to sleep."
- 94. "In regards to Question 31, I was very active before my heart condition diagnosis. I played a racquet + sport (Pickleball) 3x a week and went to the gym (crossfit) 3x a week. I haven't been able to return to these activities yet. And, we also traveled quite a bit which we still can't do."
- 95. "Services were excellent."