Assessing the impact of the First Link® program

Forging a nationwide partnership

Outcomes from a
two-day workshop held
October 3 & 4, 2012
in Toronto

Workshop Summary

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Alzheimer Society

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Building on existing relationships with researchers and policy makers

First Link® is an innovative referral program designed for people newly diagnosed with Alzheimer's disease and other dementias and their families. The purpose of this planning initiative is to evaluate this program, building on the strong relationships that Alzheimer Societies across the country have established with researchers and policy makers. A formal nationwide partnership will be created to focus on research that will inform the further development of First Link across Canada, influence related government policy, and contribute to knowledge on health system integration, dementia care, and program evaluation.

Workshop purpose

To create a formal nationwide partnership to focus on research that will inform the further development of First Link® across Canada, influence related government policy, and contribute to knowledge on health system integration, dementia care, and program evaluation.

First Link® provides early and ongoing support for people with dementia

The diagnosis of dementia can be sudden and frightening, plunging families into a sometimes confusing network of medical care and social services. People may not know what to do or who to call. Too often families struggle to cope with the challenges alone, waiting until a crisis – an emergency room visit or caregiver burnout before seeking help. These challenges are being faced by a rapidly growing number of people. Within a generation, the number of Canadians with dementia is projected to grow from 500,000 to 1,100,000, the cost to Canadians for dementia care is projected to climb from $15 billion to $153 billion, and the number of hours of informal care Canadians will provide is expected to increase from 231 million to 756 million. The predicted surge in dementia cases will overwhelm Canada's health care system unless specific and targeted action is taken (Alzheimer Society of Canada, 2010).

First Link is one such action. It provides support as early as possible and throughout the progression of the disease (McAiney, Harvey, Schulz, 2008). The philosophy of First Link is that early access to ongoing services and support has a significant impact on persons with dementia, their families and caregivers. It increases their knowledge and understanding of dementia, helps them to better cope and plan for the future, reduces stress, and prevents crises.

First Link connects people to a learning series offering information about diagnosis, day-to-day living, positive approaches to care, managing challenges, and preparing for the future. Support groups and opportunities for one-to-one counselling are also provided as are links to additional community programs and services. First Link is designed to make the job of primary-care providers easier by allowing them to connect their patient to essential information and support services. The referral process is quick and easy. Families can become more active participants in disease management and make better use of their time with physicians because they have more information and support. This may lead to fewer visits to the physician because of fewer crises.

> *First Link® was founded in Ontario ten years ago. The program has expanded across Canada and is now offered in six additional provinces: British Columbia, Alberta, Saskatchewan, Manitoba, Prince Edward Island and Newfoundland.*

> *Dr. Samir Sinha, Provincial Lead for Ontario's Seniors Strategy, recognized First Link as a "vital program and service for older adults and unpaid caregivers affected by dementia."*
>
> *Source: Living Longer, Living Well: Report Submitted to the Minister of Health and the Minister Responsible for Seniors on recommendations to inform a Seniors Strategy for Ontario.*

Building on prior program evaluations

Program evaluations conducted in British Columbia, Saskatchewan, and Ontario have shown that First Link has been successful at connecting individuals with dementia and their caregivers to services and education programs sooner than would have otherwise been the case. The British Columbia evaluation and a current study in south central Ontario analyze program costs. An evaluation of the *First Link learning series* is currently being conducted in Ontario.

However, several questions remain unanswered:

- How are the different needs of individuals with dementia, spousal caregivers, and adult children caregivers best met?
- To what extent does First Link increase the knowledge and understanding of their needs?
- To what extent does the program help each of these groups better cope and plan for the future?
- Does First Link have a demonstrable impact on quality of life?
- Does it help to reduce stress and prevent crises?

- Provincial ministries of health and regional health authorities are keenly interested in understanding what impact, if any, First Link has on health care service utilization (such as reduced emergency department visits, decreased alternative level of care days in acute care, or delays in admission to long-term care homes).
- A better understanding is also needed of the influence the program has on the use of primary care and various community services, such as adult day centres.

Workshop overview

David Harvey, Chief of Public Policy and Program Initiatives from the Alzheimer Society of Ontario, delivered opening remarks, explaining that the goals of the initiative were to

1. Learn more about how First Link enables people to live better
2. Better understand its contributions to providers
3. Understand how these two factors together influence health service utilization

Workshop topics to be covered:

1. Introduction to First Link
2. Current research – measuring effectiveness and impact of health-care programs like First Link.
3. Service and policy
4. Literature review highlights
5. Characterization of good research questions
6. Assess and prioritize
7. Discuss next steps

Participants' desired outcomes:

Evaluation

- Make evaluation easy and part of the system
- Identify key elements of the program and determine how best to evaluate them

Program development

- Ensure that we are not only doing the right thing, but doing it right
- Identify what we are doing and focus in on how we can improve the program
- Enable the program to achieve a better sense of control

Research

- Generate not only great research questions, but the right research questions
- Create more opportunities for funding collaborations and partnerships
- Understand how these sort of initiatives can inform future research directions on better treatments

Improved outcomes

- Develop easy-to-collect statistics, leading to reduced waitlists and ALC hospitalizations
- Outline an organized effort to improve health
- Improve knowledge translation for patients

Improved integration

- Enable conversations with the government
- Increase linkages between the sectors

Day 1 Proceedings

Introduction to First Link

"First Link – the Alzheimer Society working together with physicians and health professionals to ensure families are connected to services and supports as soon as possible after diagnosis, or at any time later in the disease process."

Kathy Kennedy, Director of Programs and Services at the Alzheimer Society of British Columbia presented an introduction to First Link. The objective of this session was to ensure that participants were familiar with the First Link program and provide an opportunity for questions.

People diagnosed with dementia often do not understand the disease or know where to go for support. Evidence indicates that families who receive support in the early stages of the disease continuum are better equipped to deal with the burdens and challenges of the dementia journey. The receipt of timely information enables people to know "what to do, where to go and who to call" and leads to improved planning, better communication with health-care professionals and crisis aversion.

First Link provides families with a direct referral from health-care professionals to local Alzheimer Societies immediately following a diagnosis of dementia. The key components of the program include:

- Outreach to health professionals
- Formal referrals
- Proactive contact with families
- Information and connection to services
- Intentional follow up

Once contacted by the Alzheimer Society, individuals have access to Alzheimer Society core services throughout the progression of the disease, including information and referrals, education and support services. The provision of support from the Alzheimer Society enables health professionals to focus on the medical aspects of dementia care, which helps to strengthen the connections between care providers and families.

Challenges for First Link include gaining access to family physicians and 'selling' the program to potential referrers. There have also been challenges related to motivating care providers to complete the referral form as well as challenges of a rapidly changing health-care system. Additional challenges discussed included engaging and gaining the trust of families as well as Alzheimer Society capacity issues, such as the need to "grow" the core services, recordkeeping, internal communication and the ability to manage an increasing number of referrals and follow-ups.

At a national level, challenges exist related to variations in the program model as well as differences related to staffing and recordkeeping.

Discussion

A participant asked whether First Link coordinators had a well-defined set of core competencies. The presenter responded that a set of core-skills does not exist currently; however, this is currently being discussed.

Another participant spoke of the importance of volunteer support, as various Ministries of Health are currently operating with scarce resources. At the same time, populations and health care needs are growing. Building volunteer capacity will require community resources along with creative, organized efforts for training to an acceptable level of competency. It will also require organized recruitment, management and other investments. Another participant pointed out that such initiatives would require significant investments.

A related comment followed regarding the general importance of recordkeeping and the need for standardization. It was emphasized that it is the responsibility of the program to organize its system so that the program can be easily measured and evaluated.

Overview of current research measuring effectiveness and impact of similar health care programs – challenges (Part 1)

Carrie McAiney, Associate Professor in the Department of Psychiatry and Behavioural Neurosciences at McMaster University, presented on the current research, challenges and opportunities related to the First Link program. The objective of her presentation was to provide participants with an overview of the research conducted to date and discuss challenges and opportunities for evaluating the program.

Research has consistently shown that caregivers of persons with dementia have poorer physical health, poorer mental health and greater financial burdens. However, despite the availability of education and support services, few individuals with dementia or their caregivers access help early in the course of the disease. To investigate the effect of First Link on these outcomes, Dr. McAiney conducted an evaluation of the program in two provinces: Ontario (3562 individuals, 45% from Ottawa) and Saskatchewan (502 individuals, 61% from Saskatoon). The study aimed to assess the impact of First Link on:

- Connecting family care partners to the Alzheimer Society and other services earlier in the disease process
- Knowledge & awareness among professionals
- Knowledge & awareness among family care partners
- Care partner coping and burnout
- The implementation of First Link (e.g., facilitators, barriers, improvements, sustainability)

The evaluation was based on a comparison between First Link and traditional self-referred client contacts in both provinces. Data sources included referrals and client contacts in addition to surveys of caregivers and health professionals. It also included interviews and focus groups with persons with dementia, family members, key stakeholders and project leaders. The results showed that First Link does connect people with information and support services earlier in the course of the disease.

Province where study was conducted	**Characteristics of Individuals Referred (%)**		**Age of Individuals Referred (years)**		**Average time between diagnosis and referral to Alzheimer Society (# of months)**	
	Women	Persons with Dementia	Average	Range	Self Referred	First Link Referred
Ontario	69	6	65	23-96	18	7
Saskatchewan	78	2	61	22-100	17	6

The findings of the study suggested that aspects of the First Link model were working differently. The results showed that connecting people with support services earlier in the course of the disease had made a difference for most families. Respondents recognized the importance of making a referral through First Link and thought that the referral process was extremely easy, efficient and seamless, although it was noted that the need for consent in SK presented some challenges.

Overall, respondents were very satisfied with the First Link program as well as the services provided by the Alzheimer Society. As a result of the program, caregivers reported being more knowledgeable about dementia, more familiar with community services, more confident and better able to manage the caregiver role. However, the survey showed no differences in coping effectiveness or caregiver stress between individuals referred through First Link compared to those who were self-referred, even though this result was not supported by interviews with individual caregivers.

Health professionals indicated that while First Link had no effect on diagnosing dementia, the program had given them a better understanding of how to help individuals with dementia and family care partners. In addition, health professionals noted that the program increased their understanding of the role of the Alzheimer Society as well as that of community support services.

Some of the challenges of the study were related to

1. data collection, including issues with staffing, time constraints and competing priorities,
2. low response rate on the caregiver survey
3. the subjective assessment of impacts to persons with dementia, family members and the health system.

Potential directions for further study include examining the longer-term impacts of First Link at an individual level as well as investigations into the use and cost of health and community support services from a societal perspective.

Discussion

Program integrity - The meeting participants engaged in a discussion surrounding the framework of the First Link program. It was asked whether First Link had a set of clearly defined core criteria – i.e., the components of the program. The group heard that, in Ontario, the issue of core criteria of the program is managed by the Peer Review Process. The five core components of First Link were then reiterated, as outlined in the introduction to First Link presented by Kathy Kennedy. The group heard that the Alzheimer Society Federation has now agreed on a basket of services as well as the standards around them. Ontario and Quebec have agreed on the five key components. The participants emphasized the importance of maintaining the integrity of the program model.

Data collection - For the purpose of research and evaluation of the program, it was suggested that a partnership with ICES would be advantageous, utilizing their dementia cohort. Another participant informed the group that many Alzheimer Society chapters in Ontario would soon be conducting interRAI client assessments, which would provide a means to connect with the ICES data. It was emphasized that efforts should be made to "include all of the community" in studies utilizing data from administrative databases.

Ethical issues related to recruitment - A great deal of research on Alzheimer's disease has been inhibited by limited notions of autonomy (i.e. ethical concerns and obstacles related to acquiring consent for participation in studies from people with cognitive impairments). In Alzheimer's disease, recruitment essentially comes to a halt, as 'someone else" has to sign the agreement. In a hospital environment, there tends to be a lack of understanding about how autonomy actually works, which could be resulting in adverse outcomes. The opinion was expressed that the Alzheimer Society should confront this important issue. It was then pointed out that there is currently no consensus on ethical issues related to autonomy at the Alzheimer Society. Clinical Studies Ontario will be working with the Ontario Brain Institute in an effort to streamline multi-centre clinical trials, including ethical issues related to recruitment.

Overview of current research measuring effectiveness and impact of similar health care programs – challenges (Part 2)

Lisa Masucci from the Centre for Clinical Epidemiology & Evaluation, Vancouver Coastal Health Research Institute at the University of British Columbia, presented the results of an economic analysis of the First Link program in British Columbia. The objective of this presentation was to provide an economic assessment of the First Link program on the basis of available information comparing program costs and benefits. This research presented was conducted under the supervision of **Craig Mitton**, Associate Professor, University of British Columbia.

To date, there are no formal studies that assess the economic value of earlier intervention achieved through a program like First Link in terms of impact on health service utilization and quality of life. To evaluate the potential impact of First Link in British Columbia, Ms. Masucci and Dr. Mitton conducted a literature search using the terms: *cost, cost-effectiveness, service utilization* together with other terms related to early intervention in Alzheimer's disease. There were no restrictions on the search with respect to dates.

Nine studies addressing impacts related to early intervention and service utilization were identified. The most relevant study was a cost-benefit analysis that found a strong relationship between early diagnosis and intervention and AD and net societal savings. The study compared the costs of institutionalization to the costs of home care and determined that a minimum net savings to government of approximately $54, $117, and $128 per day could be achieved for every day that institutionalization is delayed (where dementia is severe, moderate, and mild, respectively). The study predicts that the actual savings could be even greater at a societal level (up to 40% depending on level of severity).

Ms. Masucci and Dr. Mitton concluded that the First Link program has the potential to be positive in economic terms. If a minimum of 1% of families that are referred to the AS through First Link receive caregiver services, the program will likely pay for itself by offsetting costs to the healthcare system.

Discussion

The ensuing discussion among participants focused on identifying criteria for developing research questions to evaluate the First Link program. A participant pointed out that research questions would need to consider issues like the following:

- Can First Link work from an economic standpoint?
- Does it work from a community perspective?
- Does it reach everyone it is intended to?

It was also expressed that research questions evaluating the First Link program should consider impacts on acute hospitalization as well as ALC.

Group members agreed that First Link evaluations would benefit from information contained in administrative databases. For example, the Behavioural Supports Ontario project has begun looking at administrative databases to learn more about its client population and associated impacts.

Lastly, another participant reminded the group of the importance of considering caregivers in these discussions.

Highlights of literature review

Lisa Masucci from the Centre for Clinical Epidemiology & Evaluation, Vancouver Coastal Health Research Institute, University of British Columbia, presented the highlights of a scoping review of dementia literature.

Dementia literature was reviewed over four theme areas:

1. Primary care delivery in rural areas
2. Physicians – diagnosing dementia and providing early support
3. Health care costs – service utilization – economic
4. Support needs of caregivers

Literature pertaining to health care cost and economics (category 3) was searched from 1990-2012. Literature in all other categories was searched from 2000 to 2012.

Theme 1 - Primary care delivery in rural areas literature was searched using the terms *rural, remote, service delivery* and *care delivery*. This search retrieved 31 articles. The articles were then assessed to identify recurring themes and key points.

In general, this search indicated that there are fewer service options for people living in rural areas compared to urban-dwelling individuals, including formal services as well as educational opportunities. In addition, the review showed that research on rural caregivers is lacking, and the scarcity of information increases the barriers for the development of services and supports for people with dementia and their caregivers.

Recommendations for future research in this area could focus on opportunities for service delivery through telemedicine and technology use; the impact of culture on the use of services; and the differences between rural and urban settings as related to caregiver education and support needs.

Theme 2 - Physicians diagnosing dementia and early support literature was searched using the terms *diagnosis, dementia, support services,* and *health-care professionals*. This search retrieved 15 articles.

Key points in this theme area were largely related to barriers to diagnosis, including difficulties primary care providers have recognizing early symptoms as well as a lack of knowledge regarding the therapeutic benefits of early diagnosis. The review also identified articles addressing barriers to seeking diagnostic assessment, including issues with primary care providers not offering the appropriate tests, worries over the impact on life, and beliefs that memory problems are a normal part of aging.

Areas for future study include memory clinics and their potential for improving access to early diagnosis as well as increasing primary care provider knowledge of dementia. In addition, the search identified that more research is needed into the reasons that people choose not to have diagnoses.

Theme 3 - Health care costs and economics literature was searched using the terms *service utilization* or *use, cost effectiveness, dementia, care,* and *costs*. This search retrieved 11 articles.

In 2008, the total economic burden of dementia in Canada was estimated at $15 billion. Cost-effectiveness studies focusing on non-drug related interventions found no difference compared to general practitioner-provided care.

Future areas for research in this theme area include studies to determine the costs of informal and formal dementia care as well as the cost-effectiveness of dementia support programs for people with dementia and their caregivers.

Theme 4 - Support needs of caregivers literature was searched using the terms *support, , caregiver, dementia, care,* and *unmet needs*. This search retrieved 1 article.

The article featured the results of a focus group discussion with caregivers and health services professionals. Caregivers reported a need for day services that enable respite. The facility reported problems with staff turnover as well as concerns over the costs of the program. This is an area for future study.

Government health policy context

Deborah Sattler, Manager, Health Policy and Care Standards Branch, Ontario Ministry of Health and Long-Term Care (MOHLTC), presented an overview of the challenges related to seniors' care in Ontario and discussed the relationship between policy makers and researchers. The objective of this presentation was to provide a government health policy context to guide the development of First Link research questions.

The group heard that 10% of Ontarians consume $26,000 to $37,000 per capita, and that targeting high costs and high risk groups provides the best opportunity for reducing overall costs. Fiscal challenges increase significantly with aging, and it will be important to prepare the health care system in a way that works for future generations. The MOHLTC is thinking about shifting costs to the community in an effort to move from a system that works in silos, focuses on acute care and is reactive in nature, to a high-value, person-centred approach to health.

With regard to the realities of data and evidence, the government needs information very fast. It is important to recognize that research is only a single component of multi-dimensional policy decisions. It is also important to understand that the government is confronted with mountains of data. Evidence is expected to be tangible, actionable and solutions-focused. It is important to think about how data can be generalized, supporting spread and sustainability. Data should be technically strong and practical.

In moving toward a person-centred system, there will be an increased reliance on community partnerships. The current goals are in alignment with the Triple Aim Framework, which focuses on the experience of the individual and the health status of the population, leading to cascades that translate into system change. The MOHLTC understands that many initiatives will take years to mature through a process that involves constant learning and improvement together with evaluation. The MOHLTC is working toward an integrated delivery framework that brings together research and policy.

Discussion

The discussion began with an emphasis on the issues with dementia related to clinical risk and also clinical management. The speaker responded by affirming the importance of clinical risk management, which involves active monitoring of the environment. Ms. Sattler also pointed to the importance of care coordination including family partnerships with the system to reduce the risks and help with some aspects of clinical management. A participant brought forward the idea that there are three main groups of seniors: (1) the 60-70% who age well; (2) those people with 'new problems' who hit the system with no experience; and (3) the long-term care extended care group. Another participant indicated that people with dementia and their caregivers become overwhelmed in the face of the health system – to the point of inaction in many instances. The group heard that while the Ministry of Health in British Columbia appreciates First Link, it would like more evidence in support of the program. Thus, families are bearing most of the costs and burdens related to caregiving.

Characteristics of a "good" research question

Paul Stolee, Associate Professor at the School of Public Health and Health Systems, University of Waterloo, led a discussion to identify the characteristics of effective research questions. The objective of this session was to prepare participants for question generating by outlining criteria against which research questions might be evaluated. The criteria identified during this discussion were later incorporated into a rating sheet used on Day 2.

The following list of qualities was presented to the group:

- Feasible
- Interesting
- Novel
- Ethical
- Relevant

It was recommended that "feasible" be removed (i.e. be kept on the back burner) so as not to limit creativity and the flow of ideas. Feasibility could be considered at a later point in the discussion. The “criteria for good research questions” were then put to the group for input. The responses to the question, “A good research question should do what?” are listed below:

- Avoid arbitrariness
- Challenge (providers that they are demonstrating what they are supposed to do)
- Measure proximal and lagging outcomes
- Demonstrate care and system-level impact
- Harmonize person, provider, system
- Specify relevance to whom - government, providers, persons
- Keep in mind who the research serves
- Align cost and everyday practice
- Ensure knowledge translation will occur to respective audiences, yielding results that are good for the person and also have value for the health system
- Yield quantitative and numerical results
- Quantify the intervention described
- Consider context (province or region) cultural shifts / jurisdictions
- Avoid impeding client engagement
- Provide sufficiently qualitative results to augment numbers
- Yield large simple outcomes
- Impact on program staff is manageable
- Inform program for modification

The group discussed how it seemed that participants’ inputs appeared focused more on “program design as opposed to quality improvement.” It was felt that quality improvement and the appropriate metrics should be built into the day-to-day activity plan.

Following this session, the participants broke into small groups to generate as many research questions for evaluating First Link as possible. It was expected that the diverse make-up of these groups would result in diverse questions and priorities.

Day 2 proceedings

Review of Day 1 and discussion

The second day of the meeting began with a general discussion and review of the first day’s outcomes. The group agreed that this workshop was an important milestone since a group of researchers had never before come together to discuss First Link in this manner. Given the diversity of stakeholders in attendance, the meeting could be considered an example of knowledge transfer at a high level.

It was suggested that a report be prepared to describe the planning initiative and summarize its discussions. The group agreed that draft proceedings of the meeting would be compiled and distributed to the meeting participants for review and comments.

It was suggested that this group might meet again in three years to discuss progress.

It was also suggested that research questions generated in this planning meeting might be of interest to other investigators and could inform or contribute to other initiatives across Canada. Researchers must be interested. Researchers do appreciate variety. However, research must also be feasible and fundable.

The participants agreed that many of the questions generated in the break-out sessions on Day 1 were focused on program design and might not be of interest to the target funding agencies. These questions were compiled separately and were not presented to participants for scoring. There was consensus among the group that the program-focused research questions would be brought forward for consideration for partnerships with the National Initiative for the Care of the Elderly (NICE).

The discussion continued with a focus on the foundations of research design and funding. A participant commented that resources follow ideas. Research programs may comprise sequential and/or parallel projects and can have a three to five-year horizon. Research should address major issues determined to be important. Researchers must also consider multiple funding sources. Research questions should be expressed in the language of the granting agency.

It was also noted that routinely collected data is very different from data collected for a research study.

The issue was raised that the work describing First Link referrals versus self-referrals would need to be validated, particularly in other provinces. The next research project needs to build upon accumulated evidence. Future research on First Link will need to identify the flaws in any previous studies and make improvements. The research process will involve working on the same topic over time, sharing findings and building a knowledge base. A suggestion was raised that perhaps a Community of Practice (CoP) could be formed that would facilitate this work, as programs vary across the country and people will need to collect the same data measurements.

The group agreed that the challenge of evaluating the First Link program lay in reaching consensus of “what should be collected” and “how it should be measured.” A standard of measures across provinces would be needed.

It was noted that Ontario likes to make progress that can be spread to other jurisdictions.

It was suggested that it would be beneficial to identify research questions where outside resources would be required in order to get additional efforts and partners involved.

Approaches to measurement

Measures should be chosen that address the following:

1. Patient and caregiver experience, answering questions like “Has quality of life improved?”
2. Outcomes, both process (e.g., # sessions attended per year) and health (e.g., delay in institutionalization)
3. System impact. It will also be necessary to demonstrate that impacts are occurring in other provinces – standardization of measurements.

There is also a need for agreements on how to assess person-reported outcomes, including the development of appropriate questions and ways to harmonize these measures with other data. It was suggested that technology such as iPads could be used to facilitate harmonization. Techniques of “scaling psychology” can be used for designing quality of life questions. The question, “How is your quality of life?” has been shown to be an important determinant of mortality. This question can be approached in three dimensions: physical, mental and social. It was suggested that OHIP numbers could be collected to enable comparisons across jurisdictions as well as communities. However, another participant commented that with OHIP there would be issues related to informed consent as these numbers can be used for research but are not permitted for program development. Lastly, it was noted that, to enable standardization of reporting, the Local Health Integration Networks would need to be brought to the table in Ontario.

An effective evaluation of First Link would need to assess the impact of the intervention on caregivers at a system and an individual level. At an individual level, for example, the “Barrett Caregiver Burden Score” can be used for measuring a person’s degree of stress, quality of life and changes on quality of life resulting from the intervention. It will be important to capture details such as “What is happening in the person’s life, and how and how is the program helping with that?” In addition to caregivers, it will also be important to assess the impact on quality of life for persons with dementia. This will include isolating those aspects of dementia that are most troublesome and difficult to deal with. “Concept attainment” was suggested as a potential approach for structured inquiries of persons with dementia. As the foundational principles of the Alzheimer Societies are based on respect for the person with dementia and their family, it was suggested that a questionnaire, “comfort with choices,” be prepared to assess client experience and satisfaction.

At a system level, there will be a need for ongoing measurements to assess changes in populations and impact on system. The approach would need to consider the ease of collecting data from frontline workers, patients, and caregivers. It was recommended that the assessments have no more than 10 questions and that they should be designed in a way that eases the burden of answering/participation. In addition, only data that is “usable” should be collected. Indicators of crisis should be real indicators that are readily translatable to measures.

There is potential merit in developing standardized question organized around the “Triple Aim” framework, which could make comparisons across provinces more effective.

Developed by the Institute for Healthcare Improvement, the “Triple Aim Framework” comprises three core objectives for optimizing health system performance: 1) improving the health of the population; 2) enhancing the patient experience; and 3) reducing/controlling the per capita cost of care (http://www.ihi.org/explore/TripleAim/Pages/default.aspx).

A comment was brought forward concerning the importance of identifying the optimal time intervals for demonstrating the impact of First Link. Participants were reminded of the program goals of reaching people as early as possible in the course of the disease. There was some uncertainty around the duration of program utilization, which was estimated at 4 years.

The final discussion topic focused on the potential use of administrative databases in First Link research and program evaluation. The Institute of Clinical Evaluative Sciences (ICES) conducts health-care and health services research in Ontario. ICES accesses large administrative databases containing information such as emergency room visits, physician claims, long term care, hospital visits, etc. The institute is strictly bound by privacy/access to information protocols that govern the way it holds and uses data.

ICES has satellite sites at the University of Toronto, Queens University, the University of Ottawa, the University of Western Ontario. Past projects have linked administrative data from Ontario with Manitoba and Saskatchewan. The potential exists to link Ontario data with British Columbia.

Research can focus on health systems, primary care, access to care and evaluation. Study designs and methodologies allow for more detailed analysis for correlation, causal statements and factors associated with change. An sample research question could be “How long will it take for First Link to impact emergency room visits?” This question can be addressed by identifying a cohort, such as older adults with physician- or hospital-diagnosed dementia. Opportunities also exist for “smaller area” variations that allow for benchmarking of best practices.

Researcher questions generated

1. Assessing the effects of the intervention on acute care, institutionalization, emergency department
2. Assessing the impact of the intervention on caregiver stress/distress (mental and physical health, own care interventions)
3. Does the intervention empower individuals with dementia and caregivers to ask questions about potential side effects of interventions and medications? (process measure) And at a later time, are there decreases in these things (e.g., inappropriate medication use/interventions)? (outcome measure)

4. What impact does the intervention have on referrals to specialists?

5. What is the cost/benefit effect of transferring burden of care to caregivers in terms of ... (hospital visits/stays, crisis/emergency interventions, other)?

6. What symptoms of the people with dementia do family members find most troublesome? And does First Link change this profile (e.g., confidence in providing personal care)? (an individualized approach to outcomes)

7. Does the intervention have an impact on indicators of crises? (911, COAST, etc.)

8. Does First Link impact quality of life (as defined by?) for the person with dementia?

Non-researcher questions generated

Impact on people with dementia, family and care partners

1. Measuring First Link activities
    a. Number of activities (e.g. contact with person with dementia or care partner)
    b. Effectiveness of activities (e.g. stress relief, confidence building, etc.)
    c. Key aspects of First Link that make the most difference

2. Measuring different aspects of stress using components (of First Link)

3. What role do Alzheimer Societies play (or can they play) in navigation and coordination of care?

4. How do social supports change the outcome between caregiver and afflicted?

5. What is the cost and burden effect on caregivers and providers?

6. Which areas can First Link impact and not impact (e.g. financial, behavioural support, understanding)?

Awareness and utilization

7. Assessing awareness of First Link
    a. Where is utilization higher?
    b. Benchmarking practices that raise awareness

8. Non-referrals to First Link alternatives and barriers to utilization

9. What are the different experiences of self-referral and First Link?

Models, modalities and follow up

10. Assessing effectiveness of follow up

    a. Content
    b. Frequency, intervals
    c. Modality

11. Assessing effectiveness of diverse models of care (e.g. embedded v. non-embedded)

    Which models are easier?

    i. For care partners
    ii. For people with dementia
    iii. For providers
    iv. For primary care providers

12. Modalities: effectiveness of group or one-on-one?

13. Benchmarking standard and unique measures in and amongst jurisdictions

14. Current best practices and vascular supports for patients and caregivers in the early stages

Provider and internal practices

15. Measuring the experience of First Link providers

16. Are First Link services driven by client needs rather than provider needs/expedience?

17. What are critical factors regarding knowledge exchange between stakeholders and policy makers (between and amongst First Link Providers and to policy makers)?

18. Benchmarking leadership and service competencies of successful First Link coordinators

19. Benchmarking employee to First Link user (family & person with dementia) ratio, i.e. number of employees to number of users

20. What are the critical strategies between continuous change and product delivery?

Selecting research questions

Workshop participants agreed to use the following **criteria** to rank potential research questions:

- Magnitude (addresses important question/area with relevance to large population)
- Relevance to the work and mandate of the Alzheimer Society
- Relevance to clients and families
- Relevance to government
- Potential impact (addresses knowledge and/or practice gap; likely positive impact on persons with dementia and/or care partners)
- Potential for knowledge transfer
- Innovation (question/topic addresses something unique/innovative)
- Addresses barriers to access of care, health system integration or capacity
- Does not impede client engagement
- Manageable impact on program staff

Highest-ranked research questions

a) Impact on caregiver stress/distress, incl. a quality of life perspective that considers both the caregiver and person with dementia

b) Impact on acute care, institutionalization, emergency departments as well as referrals to specialists and community services

c) Cost-benefit analysis of transferring the burden of care to caregivers (weighed against hospital utilization)

Moving forward with the partnership

Commitments were made to confirm **core components of the partnership**:

1. Institute for Clinical Evaluative Sciences (ICES) to advise on data resources and use of data across jurisdictions.
2. Researchers to work together with the support of the Alzheimer Societies of Ontario (ASO) and British Columbia (ASBC).
3. Government, regional health authorities, local health integration networks to be consulted regarding priority research questions.

Taking the next steps

- ASO and ASBC will assess readiness for research by Spring 2013.
- Carrie McAiney and Craig Mitton will lead researches in Ontario and British Columbia and will pursue funding with CIHR research programs, Alzheimer Society Canada (ASC) and other organizations.
- ASO and ASBC will continue to analyze methods and procedures of data collection.
- ASBC will organize a future workshop with provincial Alzheimer Societies.

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Select articles

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