

**The Care to Know Centre
2009/2010 ACT Research Grants Program**

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About the ACT Research Grants Program

As our inaugural program, the Care to Know Centre (CTKC) launched the ACT Research Grants Program in 2008. The ACT program supports **Applied Client-focused Team** research projects. Our goal is to create change in the health system right through to the point of contact with the client via the delivery of care. Our philosophy is to encourage the development of new partnerships, to support the capacity building and shared learning of partners and to fully engage in activities driving knowledge to action. We also look for the potential to sustain and replicate projects.

The 2009/2010 ACT Research Grants Program will provide a total of \$200,000 in seed funding to support applied research initiatives that impact the experiences and needs of the health client at the point of contact with the health care system. Individual grant awards, up to a maximum of \$50,000, will be awarded to projects spanning 12 to 18 months.

Projects will be considered that include the client in a key role such as informant or subject and/or a focus on the interaction between the client and the health care provider. The CTKC is particularly interested in projects that impact clients who would benefit from, or who currently use, home and community health care services. However, projects that focus on other health delivery sites such as hospitals are welcome to apply. The project should, at minimum, consider the implications of the findings on the delivery and practice of care in the home and community care sector.

We will consider applications from a variety of organizations working to improve health for home and community care clients. We seek to fund excellence and welcome applications from around the world.

The CTKC, through the ACT Research Grants Program, supports applied research initiatives that:

- exhibit a commitment to working with and addressing client health care needs;
- demonstrate collaboration between key stakeholders including researchers, decision-makers, clients and others as appropriate to the proposed project;
- contribute to new knowledge creation by filling gaps in existing knowledge;
- are likely to effectively support knowledge utilization by making an impact on the client's perception and experience of health care;
- build capacity within the organization, system, and client group;
- have sustainable outcomes; and
- have the potential to be used as a replicable model for others in future.

ACT Research Grants Program Request for Proposal (RFP) Guidelines

The guidelines for the ACT Research Grants Program are designed to ensure that we achieve the CTKC's vision to harness the knowledge of leaders including clients, decision-makers, care providers and researchers to transform and promote a unique client-focused health care experience.

Additionally, the guidelines reinforce the need for a strong commitment to develop and execute a knowledge utilization and exchange plan to profile and transfer the project findings and implications during the project and after its completion. Building capacity within your organization, the broader community and health care system are important tenants of our program to ensure the impact will be sustained. This will include thoughtful consideration and plans for how the findings from the project can be put into action in the successful applicant's organization or replicated in collaboration with others.

Governance and Administration

The CTKC is responsible for the overall governance of the ACT Research Grants Program. The CTKC has an Advisory Committee and an ACT Research Grants Program Review Panel made up of expert volunteers who have academic and program experience within health care as well as insights into the client experience. The ACT Research Grants Review Panel is co-chaired by Nancy Lefebvre, Chief Clinical Executive and Senior Vice President Knowledge and Practice at Saint Elizabeth Health Care and Dr. John Hirdes, Ontario Chair in Home Care Research and Knowledge Exchange.

Throughout the implementation of funded grant projects, progress is monitored by program administrators. On completion, the results are disseminated to key care providers and decision makers to support knowledge transfer and change in the health care system.

The Letter of Intent (LOI) is being released on Monday, August, 17, 2009 with a submission deadline of Friday, November 13, 2009. The Request for Proposal (RFP) is being released on Wednesday, December 23, 2008 with a submission deadline of Friday, February 26, 2009. The ACT Research Grants Program Review Panel will review all qualified proposals and make funding approval decisions. The number of grants awarded each year will depend on the quality of proposals received and grant funding available.

Research Themes for 2009/2010

The CTKC will review and fund requests for applied research projects relating to the outlined themes. Projects should fall under at least one of the following four theme areas:

- 1. Client Self-Care Strategies and Programs**
- 2. Information Communication Technology**
- 3. System Approaches to Client-Centred Care**
- 4. Informal Caregiver Support Programs and Services**

For more information on the above themes, please see **Appendix A**.

Types of projects funded

Projects may range from improving specific health and supportive home-based care to gaining a better understanding of the instantaneous and transformative nature of technology. Projects must include clients in a key role (as subjects or informants) and/or focus on the interaction between clients and health care professionals.

Examples of types of projects eligible for funding include:

- Program development, implementation and evaluation
- Toolkit development and evaluation
- Systematic literature reviews
- Evidenced based public policy statements and advocacy guides
- Investigations of models of care – alternative provider and/or delivery model with an emphasis on the role of the client and caregivers, both formal and informal.

Organizational Capacity

Applicants must demonstrate the necessary financial and management infrastructures to successfully complete the proposed initiative and manage the budget. Applicants must also demonstrate their ability to put the knowledge to use through knowledge transfer activities such as past publications as well as examples of knowledge uptake/utilization such as successful changes in practice or program implementations. In addition, commitment of key project partners as well as designated resources dedicated to knowledge transfer and exchange will be considered by the ACT Research Grants Program Review Panel.

Project Teams, Partnerships and Collaboration

Project teams should be composed of the members who bring the competencies and skills needed to successfully carry out the proposed activities. Projects that combine members from academic, decision-maker and corporate organizations are considered to have additional strength that will be recognized during the application review process.

Projects MUST include a decision-maker partner. Collaboration is encouraged with the population of interest, the decision-maker, other relevant organizations and researchers. When relevant and appropriate, those affected by the proposed initiative should be involved in the development, implementation and evaluation of the project.

Knowledge Transfer, Capacity Building and Sustainability

Applicants and partners must demonstrate their commitment to knowledge utilization and exchange with multiple audiences and through multiple forums such as: collaborative implementation with organizations that may benefit from the program; publications; posting project summary on the CTKC website; and conference presentations. Most importantly, include efforts to ensure that the knowledge gained will work to influence practice within the home and community health sector and have the potential to impact the broader health system.

The ACT Research Grants Program is very interested in community participation and the associated capacity building to achieve sustainable client outcomes achieved via sharing knowledge amongst diverse partners. For this reason, the client is required to play a role in the project. Capacity building also includes human resource development such as the strengthening of research skills for practitioners and application skills for researchers.

Analysis and Evaluation

Consistent with the CTKC' vision, to impact the client's health and care experience where it matters most, in relation to their own role in affecting their health, project teams are encouraged to use a client based outcome approach in developing a program logic model and evaluation framework.

Single year projects are funded, with consideration for up to 18 months (see Grant period and Multi-Year Funding). While client outcome evaluation may not be possible during the implementation/development phase, plans to establish a client based outcome evaluation framework should be included, with process measures to assess achievement of the objectives of the project during the funding period.

Grant period and Multi-Year Funding

The ACT Research Grants Program funds single year projects or a relevant phase of a multi-year project. Applied research projects that may take longer than one year to fully develop may be considered on the basis of the potential to achieve planned results and the likelihood of making a meaningful and sustainable contribution to positive change for the client. Projects should not exceed an 18 month period.

Grant Funding Available

Grants to a maximum of \$50,000 will be considered.

Matching Funding and In-kind Contributions

Additional appropriate support from the community, including supplemental or in-kind contributions of 50 to 100% (e.g. \$25,000 to \$50,000 in matching funding contributions for requested grant funding of \$50,000) is required. The RFP must identify the source of matching funding contribution and provide confirmation of the commitment in a letter from each source, signed by the organization's CEO.

Matching funding contributions may be direct grants to the project, or in-kind contributions (e.g. supplies and services) that relate specifically to the grant project. The following are eligible for matching funding or in-kind contributions:

- Overhead, including an organization's ongoing operational or core expenses
- Office equipment and furniture
- Knowledge transfer to support publication of grant findings

Restrictions on Use of CTKC Grant Funds

The following are not eligible for funding through the CTKC's ACT Research Grants Program funding:

- Overhead, including an organization's ongoing operational or core expenses (ex. employee salaries)
- Direct health care service delivery expenses i.e. paid caregivers
- Retroactive funding, or for any project expenses to be incurred prior to the agreed upon project start date
- Debt retirement (including deficits) or reserves; mortgage pay-downs
- Office equipment and furniture
- Activities of religious organizations that serve primarily their membership and/or their direct religious purposes, unless the community at large will benefit significantly
- Annual fund drives
- Fundraising dinners or event sponsorship
- Sabbatical leaves, student exchanges
- Medical facilities or equipment, buildings, renovations or equipment replacement
- Political causes
- Library acquisitions and construction
- Publication of books, however CTKC funds can be used as part of your knowledge transfer plan to support publication of grant findings
- CTKC funds cannot be used to make a contribution to an endowment fund. Endowment funds can provide matching grants for a CTKC funded grant
- Capital requests, with exceptions. Capital requests that are part of the broader project and required for the implementation or delivery of the project to the community will be considered. Funding just for capital costs that are not part of a larger applied research project will not be considered

- Activities previously supported through government funding, separate but related activities may be considered
- Activities previously supported through government funding, separate but related activities may be considered

Eligibility

The proposed project must:

- Address one of the CTKC's 2009/2010 ACT Research Grants Program themes with an overarching theme of Client-Centred Care
- Include clients in a key role (as subjects or informants) and/or focus on the interaction between clients and health care professionals
- Include a community partner on the project team
- Have the capacity to achieve the proposed results
- Verify that matching funding or in-kind contributions of 50 to 100% of the requested funding have been secured
- Review and accept the CTKC's Letter of Agreement.
- Proposals are invited from Canada, and worldwide

Projects not eligible for funding include:

- Clinical trials
- Replication of an existing program
- Needs assessment
- Epidemiological studies
- Proposals whose primary purpose is to hold conferences, symposia, competitions, annual events or for memberships and travel to attend these events

Note: participation in, or holding events to support knowledge transfer and capacity building may be included in your knowledge transfer plan and funded through your grant.

Ethics

The CTKC adheres to the highest standards of ethical practice. On occasion, conflict of interest or perception of a conflict may arise. Saint Elizabeth Health Care adheres to a privacy standard and privacy policy. The CTKC has a set of guidelines for our advisors and staff as well as the Directors and staff of grantee organizations.

You will indicate if your project requires ethics approval as well as the status of ethics review in your proposal.

Submission Requirements

The ACT Research Grants Program involves a two stage application process:

1) Letter of Intent (LOI)

A Letter of Intent (LOI) is required for each grant category. An applicant is not obligated to submit a Request for Proposal (RFP) if an LOI is submitted. However, an applicant must submit an LOI in order to submit an RFP. An RFP that is submitted without an LOI will result in an automatic denial of funding and the application will be returned to the investigator.

The LOI must be submitted via email to Amrika Ganness, Program Associate at aganness@saintelizabeth.com in its entirety. The following documents must be included with submission:

- Indicate the estimated budget including total amount to be requested, potential matching/in-kind funding partners (max. 1 pg)
- Literature References - please provide a listing of up to 15 references that have informed your project and/or have been cited in the LOI (max. 1 pg)

LOIs must be submitted by November 13, 2009, 5pm EST. If an LOI does not meet the content and format requirements as stipulated in the LOI guidelines, the LOI will not be reviewed and it will be returned to the applicant.

The ACT Research Grants Program Review Panel evaluates each LOI to determine the appropriateness and relevance of a proposed topic for funding. Feedback will be provided to applicants by December 23, 2009.

2) Request for Proposal (RFP)

The Request for Proposal (RFP) must be submitted online in its entirety. The following documents must be attached before submission:

- Most recent annual report if applicable
- Most recent audited financial statement of the primary applicant organization
- Current year operating budget of primary applicant organization
- Team Description (2 page maximum)
- Critical Path (1 page, may be legal size)
- Project Budget (2 page maximum)
- Logic Model for project (1 page maximum, may be legal size)
- Literature References (2 page maximum)
- Funding Source letters
- Proposal Content (8 page maximum)

This section will address each of the following topics:

1. Background

2. Purpose
3. Significance
4. Research Design and Methodology
5. Analysis and Evaluation
6. Knowledge Transfer and Exchange
7. Sustainability and Capacity Building
8. Project Feasibility

RFPs must be submitted by **February 26th, 2010 by 5:00 pm EST**. Applicants will be contacted with final funding decisions on or before April 19th, 2010.

Grant process and Timelines

Activity	Deadline*
LOI Launch	August 17, 2009
LOI Deadline for Submission	November 13, 2009
LOI Feedback to Applicants	December 23, 2009
Request for Proposals (RFP) Launch	December 23, 2009
RFP Deadline for Submission	February 26, 2010
Review Panel Meeting	April 9, 2010
Notification to Applicants	April 19, 2010

*Timelines beyond the LOI deadline for submission date are subject to change.

Receiving a Grant from the Care to Know Centre

The primary applicant organization approved for funding must sign the Care to Know Centre's Letter of Agreement. This contract details conditions related to:

- Amount of grant funding, cash flow schedule, and funding period;
- Reporting requirements and audit;
- Information sharing to support knowledge transfer;
- Intellectual copyright and ownership of study data and findings; and
- Other areas

During the course of the grant we will work with the project primary contact to gather input and assistance to facilitate information sharing and knowledge transfer. Site visits with Saint Elizabeth Health Care and CTKC staff will be scheduled to recognize the successful teams and promote your project on site. Successful proposals, progress reports, and final reports will be posted on the CTKC web site, and articles published in our newsletter.

Grantor Recognition Guidelines

Organizations and researchers who are awarded funding from the CTKC ACT Research Grants Program are asked to adhere to the following grantor recognition guidelines:

- Wherever possible, ensure that all research publications of funded projects are freely accessible through the Publisher's website and are linked to the CTKC web site;
- If the publication is not freely available, please provide the CTKC with a link to the abstract for posting on our web site;
- Acknowledge Saint Elizabeth Health Care funding support through the CTKC in journal publications;
- Saint Elizabeth Health Care and the CTKC are also to be appropriately acknowledged in all press releases, publications, reports, presentations and materials arising from the grants provided;
- If the final report is not submitted to the CTKC in a timely manner, the Principal Investigator and Co-Principal Investigator will not be eligible for future funding from CTKC Centre; and
- In order to facilitate knowledge utilization, transfer and exchange, we ask that the CTKC be notified one month in advance of the publication date of any major publication or event arising from the research funded for a period of two years after the completion of the project.

Frequently Asked Questions

What is the maximum grant awarded?

Grants up to a maximum of \$50,000 will be awarded to projects spanning 12 to 18 months.

Are there restrictions for use of funding through the Care to Know Centre's (CTKC) ACT Research Grants Program?

The following are not eligible for funding through the CTKC's ACT Research Grants Program funding:

- Overhead, including an organization's ongoing operational or core expenses (ex. employee salaries, etc.)
- Direct health care service delivery expenses (i.e. paid care givers)
- Retroactive funding, or for any project expenses to be incurred prior to the agreed upon project start date
- Debt retirement (including deficits) or reserves and mortgage pay-downs
- Office equipment and furniture
- Activities of religious organizations that primarily serve their membership and/or their direct religious purposes, unless the community at large will benefit significantly
- Annual fund drives
- Fundraising dinners or event sponsorship
- Sabbatical leaves or student exchanges

- Medical facilities or equipment, buildings, renovations or equipment replacement
- Political causes
- Library acquisitions and construction
- Publication of books
- Knowledge transfer to support publication of grant findings
- Making contributions to an endowment fund; endowment funds can provide matching grants for a CTKC funded grant
- Capital requests, with exceptions – capital requests that are part of the broader project and required for the implementation or delivery of the project to the community will be considered; funding just for capital costs that are not part of a larger applied research project will not be considered
- Activities previously supported through government funding; separate but related activities may be considered

What is the minimum matching funding or in-kind contribution required?

Additional appropriate support from the community, including supplemental or in-kind contributions of 50 to 100% (e.g. \$25,000 to \$50,000 in matching funding contributions for requested grant funding of \$50,000) is required. The RFP must identify the source of matching funding contribution and provide confirmation of the commitment in a letter from each source, signed by the organization's CEO.

Can matching funding or in-kind contributions be non-monetary in value?

Matching funding contributions may be direct grants to the project, or in-kind contributions (e.g. supplies and services) that relate specifically to the grant project. The following are eligible for matching funding or in-kind contributions:

- Overhead, including an organization's ongoing operational or core expenses
- Office equipment and furniture
- Knowledge transfer to support publication of grant findings

What if my project spans beyond 12 to 18 months?

The CTKC funds single year projects. Research projects that may take longer than one year to fully develop may be considered on the basis of the potential to achieve planned results and the likelihood of making a meaningful and sustainable contribution to positive change for the client. Projects should not exceed an 18 month period. Applicants should consider applying for funding for a particular phase of their project if the completion date will take significantly longer than the 12 to 18 month funding window.

Am I eligible for an ACT Research Grant?

The proposed project must:

- Address one of the CTKC's 2009/2010 Grants Program themes;
- Have the capacity to achieve the proposed results;
- Verify that matching contributions have been secured; and
- Review and accept the CTKC's letter of agreement

Proposals are invited from Canada, and worldwide. Areas not eligible for funding include clinical trials, replication of existing program, needs assessments and epidemiological studies.

Will an ACT Research Grant fund any project?

The CTKC will review and fund requests for applied research projects relating to the outlined themes. Projects should fall under at least one of the following four theme areas:

1. Client Self-Care Strategies and Programs
2. Information Communication Technology
3. System Approaches to Client-Centred Care
4. Informal Caregiver Support Programs and Services

What types of projects are funded?

Projects may range from improving health and supportive home-based care to a better understanding of the instantaneous and transformative nature of technology.

Examples of types of projects eligible for funding include:

- Program development and evaluation
- Program implementation pilot evaluations
- Systematic literature reviews
- Evidenced based public policy statements and advocacy guides
- Investigations of models of care – alternative provider and/or delivery model with an emphasis on the role of personal support workers

What are you looking for in a project team?

Project teams should be composed of the members who bring the competencies and skills needed to successfully carry out the proposed activities. Teams must include a researcher and a decision-maker partner. Decision-makers include leaders from provider and service organizations. Projects that combine members from academic, community and corporate organizations are considered to have additional strength that will be recognized during the application review process.

When appropriate, those affected by the proposed initiative, such as a client population, should be involved in the development, implementation and evaluation of the proposal. At minimum, health clients should be involved in at least one phase of the project.

What is required in terms of knowledge transfer and exchange as well as capacity building?

Applicants and partners must demonstrate their commitment to knowledge transfer and exchange with multiple audiences and through diverse forums such as:

- Collaborative implementation of programs or tools with organizations that may benefit from the program

- Consultations with organizations for replication
- Publications
- Posting project summary on The Care to Know Centre website
- Conference presentations

The goal of the ACT Research Grants Program is to ensure that the knowledge gained through the project will be leveraged to influence practice within the home and community health sector and have the potential to impact the broader health system.

Does the CTKC own intellectual data and findings as a result of the funded project?

The CTKC does not claim ownership of intellectual property based on the findings of your ACT Research Grant project. However, knowledge transfer and exchange is an integral part of the program. Therefore, acceptance of an ACT Research Grant involves a partnership with the CTKC to promote and exchange the findings for maximum exposure and sharing of results.

What does the CTKC deem as a conflict of interest?

The CTKC adheres to the highest standards of ethical practice. On occasion, conflict of interest or perception of a conflict may arise. We have a comprehensive set of guidelines for our advisors and staff as well as the directors and staff of grantee organizations.

If approved for an ACT Research Grant, will I receive the total funding in one payment?

Grantees will be informed of the acceptance or rejection of their proposal prior to the processing of the funding. A cheque will be issued via Saint Elizabeth Health Care to the grantee. The payment schedule is based on two equal installments, with a 10% holdback payable on receipt and acceptance of the final report. The first payment will be paid out at the beginning of the project, 60 days after the notification of the grant award, and the second payment will be received halfway through the project, at six or nine months depending on the length of the individual project, after the mid-project reporting requirement.

When is the RFP submission deadline?

Online RFPs must be received by **February 26, 2010; 5:00 pm EST.**

When will I be notified if my grant proposal is approved?

Applicants will be contacted with final funding decisions **on or before April 19, 2010**

Appendix A – 2009/2010 Themes Guidelines

Overview

The Care to Know Centre, via the Applied Client-focused Team (ACT) Research Grants Program, is committed to supporting projects that encourage consideration of client perspectives, partnerships, and collaboration to best meet client needs and improve the quality of care. The Care to Know Centre will review and fund requests for applied research projects relating to client-centred care, self-care, and information communication technology, which include clients in a key role (as subjects or informants) and/or focus on the interaction between clients and health care professionals. In our definition of client, we broadly include the client, their family, friends and informal caregivers.

The Care to Know Centre is particularly interested in projects that impact clients who would benefit from or who currently use home and community health care services. However, projects that focus on other health delivery sites are welcome to apply. The project should, at a minimum, consider the implications of the findings on the delivery and practice of care in the home and community care sector.

Theme 1: Client Self-Care Strategies and Programs

In Canada, there has been a growing focus on self-care over the last few decades, with a particular emphasis on the role of the individual client in health care.¹ While self-care strategies can be used to promote health and prevent illness, there has been increasing attention on their use to manage chronic health conditions, which are the greatest single cause of death, disability, and illness in Canada.^{2,3,4} As the number of adults over age 60 is expected to rise substantially and the prevalence of chronic disease increases with age,^{5,6} research focused on maintaining health and managing chronic illness through self-care strategies has become increasingly critical to improve system efficiencies and to better support health clients.

Self-care refers to all clients do to promote health, prevent illness, and manage all aspects of living with a chronic health condition, including symptoms, treatment, physical and social consequences, and lifestyle changes.^{7,8} Health care providers can also support self-care by taking a client-centred, “collaborative approach to care that promotes [client] activation, education and empowerment”.⁹ Self-care strategies and programs can empower clients to enhance their health, monitor their illnesses, and make the necessary cognitive, behavioural, and emotional changes to maintain a satisfactory quality of life.⁷ Clients take responsibility for treatment adherence¹⁰ and living well with illness and health events by questioning the direction of their health care, making choices about every aspect of the care they receive, and ensuring treatment suits their lifestyles and is in line with their goals and priorities.^{11,12,13}

Those suffering from a chronic illness or recuperating from another health event, such as an injury, may employ a number of self-care strategies to cope with their condition. Some may have been suggested to clients by health care professionals on an informal basis, as part of their regular care, while others may simply be undertaken by clients without any direction from their care providers. These might include lifestyle modifications, treatment adherence and/or seeking support from social networks or support groups.^{14,15,16} Clients may also participate in more formal illness self-management programs that may be facilitated by either health care professionals or consumer-led groups. Self-management programs often focus on consumer empowerment and may teach specific self-care skills and behaviours, techniques to cope with symptoms, appropriate use of medication, nutrition, and/or communication and social skills. Clients may also be supported through the provision of disease-specific education and other resources to assist with self-care and navigating through the health care system.^{17,16,18}

Past research has demonstrated that self-care practices can be effective in enabling clients to minimize pain, improve quality of life, enhance elements of health status, and reduce utilization of medical services.^{11,19,20,16,17,21} Self-care can also be a means of containing costs²² and increasing the sustainability of the health care system, as it can reduce hospitalizations, emergency department use, visits to medical doctors, and overall managed care costs.^{7,19,20,16,11}

With an increasing prevalence of chronic illness in the population,² which places a huge burden on the health care system,²³ and a shift towards client self-care and health promotion, we feel it is vital to continue the development and evaluation of these practices, with a particular focus on the client experience of self-care and the partnership between clients and health care providers. This will provide a better understanding of client priorities and goals, reasons for treatment non-compliance or alteration, the nature of client/provider interactions, and ways to assist clients as they navigate through the health care system.

Proposals related to Client Self-Care Strategies and Programs may focus on one of the following areas and should include client input and perceptions wherever possible:

- Promotion of client and family empowerment, autonomy, and decision-making capacity with regards to clients' health care through the use of self-care strategies and programs
- Examination of the types of self-care and health promotion strategies and programs in which clients and families engage (e.g. lifestyle modifications, seeking support from social networks, peer support programs, formal self-management programs)
- Effectiveness of these strategies and programs (outcomes could relate to health status, self-management behaviours, self-efficacy, health care

- utilization, cost effectiveness, client and family satisfaction, or disease-specific measures)
- Availability, appropriateness, and/or effectiveness of supports and resources for self-care or to assist clients and families in navigating through the health care system
- Factors affecting treatment adherence and/or engagement with health care professionals from a client and family perspective and the clinical outcomes associated with this adherence²⁴
- Barriers/challenges to successful self-management of illnesses, health promotion and disease prevention, as they relate to self-care programs and strategies
- Effectiveness of assessment tools designed to measure client and family empowerment or client and family perceptions of self-care strategies

Theme 2: Information Communication Technology

Technology is playing a growing role in the way in which health care partnerships are created and maintained. It is possible to enhance client and caregiver collaboration through the use of information communication technology, as it increases the availability of clinical information, encourages the use of decision support tools, and allows for communication and practice across distances.

Computer technology can aid health care providers in meeting clients' expectations for services that are readily available, accessible, and seamlessly coordinated. In addition, it provides alternative ways for health information and services to be delivered directly to clients in their home, such as through the use of the internet²⁵ or telephone-delivered interventions.²⁶

Information communication technology can also be related directly to self-care, assisting home care clients to continue to live independently at home and increasing their confidence in their ability to self-manage their conditions. This may be accomplished through the provision of information, allowing them to more actively participate in care planning, and telehomecare strategies.²⁷ For example, technologies/equipment in the home can allow client self-monitoring and transmission of health data (e.g. blood pressure, cardiorespiratory signals), which would provide progress indicators to health care professionals without the need for recurrent home visits or visits to the doctor's office or hospital.^{28,29,30,27}

Technology, such as home dialysis, can provide some clients with the ability to treat their illness at home, rather than requiring frequent clinic visits.¹² Self-care may also be supported through the use of computer programs to assist with client preference assessment and "decision aids" that help clients think carefully about complex health issues, understand and clarify values, treatment and screening options, and likely outcomes.^{31,13}

While it is important to understand the transformative impact of technology as a positive influence, it is also crucial to explore client perspectives on information communication technology, its desirability, and its congruence with their lives and understanding of their illness.^{32,33} It is essential to assess how technology modifies client expectations, client/care provider interactions, and the actions that

each may take, as well as the actual effect the technology has on health and wellness.³³ We should not just to assume that technology is beneficial and will be welcomed by clients and health care providers alike. For example, the use of technology assumes computer literacy, which may be a barrier to some users.²⁷ Technology may also be perceived as having a negative impact on the client/provider relationship, as it may reduce the need for face-to-face communication, which may be an important part of their care to some clients.

Through the ACT Research Grants Program, we aim to promote an approach that incorporates consultation with clients and care providers during the design phase of new technology, as opposed to only following implementation. This will allow for an assessment of needs and interest, taking into account the fact that technology may be perceived as desirable by some groups (e.g. designers) and not others (e.g. clients).³³ We encourage the investigation of initiatives that combine technology with other types of communication and include one-to-one interaction.

Proposals related to Information Communication Technology may focus on one of the following areas and should include client input and perceptions wherever possible:

- Promotion and support of client and family empowerment, autonomy, and decision-making capacity with regards to clients' health care through the use of information communication technology
- Development and evaluation of a client and family decision aid or preference assessment tool for health-related treatment or screening decisions; tools to aid clinicians in interpreting the elicited client preference data
- Effectiveness of technologies for client self-monitoring and transmission of health data or home treatments
- Alternative ways of delivering tailored health information and services directly to clients and families in their home (e.g. use of the internet, use of electronic health records, telephone-delivered interventions), including effectiveness of these methods
- Examination of the impact of health technologies on client/provider interactions and the nature of their relationship; the role of technology in facilitating or hindering collaboration

Theme 3: System Approaches to Client-Centred Care

Client-centred care involves the manner in which care is organized and delivered with a focus on client empowerment and respect for his/her autonomy, needs, concerns, values, and priorities. Ideally, at an individual level, clients are viewed as whole persons, not diagnoses, and are leaders in their healthcare. Clients decide if and who will participate in their care, defining the goals that shape the practices of the health care team. Evidence has shown that, at an individual level, client-centred care has been effective in increasing client satisfaction and

improving the quality of care.^{34,35} There are many efforts to create and deliver client-centred care in partnership with health providers across Canada and internationally. One strong example of this commitment is the Registered Nurses' Association of Ontario's Best Practice Guideline on Client Centred Care.³⁴

In order to continue to improve care and impact clients in a positive way at the point of care, it is important to evolve individual organizational models of client-centred care to a system-wide, collaborative approach. Such a shift in focus would involve efforts across delivery sites, policy and professional designations. It would be a complex undertaking that would require significant input from clients, caregivers, health care providers, governments, and stakeholders to identify and investigate new models, procedures, and policies to ensure that an integrated team approach to health care is achieved. However, it is this type of approach, one that is open to an exploration of new ways to integrate, communicate, transition, partner and to create unique models that honour the experience of clients that may have the most potential to transform the client experience of health care. The Care to Know Centre is interested in projects that will advance efforts and provide effective strategies relating to evidence-informed policy, procedures, and practices that will promote the adoption of client-centred approaches across the health system. Projects must involve investigations of strategies and practices between two or more organizations, examining the interrelationship of key stakeholders, and should involve the client and/or their network of family and informal care givers.

Proposals related to System Approaches to Client-Centred Care may focus on one of the following areas and should include client input and perceptions wherever possible:

- System approaches to client and family-centred care, including models, policies and delivery practices
- Factors that inhibit or promote collaboration and client and family-centred care across organizations (e.g. roles, responsibilities, attributes, attitudes, expectations, and needs)
- Appropriateness and/or effectiveness of current models of client-centred care delivery, practice, and policy.

Theme 4: Informal Caregiver Support Programs and Services

With an aging population and a growing number of clients being cared for in the community, informal caregivers are playing an increasingly vital role in caring for clients in their homes. Informal caregivers are most often “unpaid individual family members who aid in patients’ physical care and disease process coping”.³⁶ They can be seen as providing three main types of social support to their loved one: informational, instrumental (such as driving patient to doctor’s appointments

and preparing meals) and emotional.³⁶ In terms of prevention and health promotion, the family is also important in encouraging healthy behaviors.³⁶

Given the significant role caregivers play in the client's care, it is important for health care providers to understand the concerns and needs of caregivers in order to provide as much support as possible, which is likely, in turn, to improve patient care. This can be accomplished through on-going collaboration and effective communication between formal and informal caregivers.

While caring for a family member can be a rewarding experience, caregivers often also experience many negative emotions such as burden, stress and worry.³⁷ Caring for someone with a chronic disability has been shown to have significant effects on the caregiver's health, particularly their psychological health.³⁸ Caregivers may struggle with role changes, feelings of losing control, a sense of inadequacy in providing care, guilt, denial, anger, fear and anxiety.³⁷ Dealing with emotional or behavioural problems with the client has also been shown to consistently increase caregiver distress and/or burden.³⁹

Research points to fact that interactions between caregivers and formal providers have often failed to properly prepare and support caregivers for their care provider role.^{40,41} Health care professionals may not fully recognize the complexity of work carried out by caregivers and may not acknowledge them as integral members of the care team. In some cases, health care providers may focus solely on the needs of their clients and may not see it as part of their job to attend to the needs of the patient's informal caregivers.^{36,40} If caregivers' needs or concerns are overlooked, they will be ill-prepared to provide care for the client.

Research has indicated several key areas in which caregivers may need support from providers or other resources. Specific caregiver requirements will depend on individual characteristics and the unique caregiving situation, however there are some common needs that can be anticipated. For example, caregivers will likely have many learning requirements, such as a general need for health-related information so that they can provide adequate and appropriate support and care to the patient and be involved in decision-making.³⁶ Some specific types of information that may be needed is information about the disease, delivery of home care, medications and side effects, depression, health promotion, community resources and financial resources.^{37,39,42} Caregivers also wish to be informed of the client's condition. This type of information can reduce the caregiver's distress and increase control and informed decision-making, thus making the caregiving experience more rewarding and the care they can provide more effective.^{39, 42}

In addition to learning needs, a systematic review of the literature demonstrated that caregivers have a need for opportunities to get out more themselves and for respite care.³⁷ They also reported a need for assistance with running errands, shopping and cooking and a desire for more stimulation for their relative.³⁷

Given the different forms of many diseases, the various treatment options, the changing nature of the information, as well as the unique characteristics of the caregiver, client and health team, more dynamic approaches to caregiver support are needed.

Proposals related to Caregiver Support Programs and Services may focus on one of the following areas and should include client and/or caregiver input and perceptions wherever possible:

- The development of programs, resources and strategies that promote caregiver empowerment, autonomy, and decision-making capacity with regards to clients' health care and family supports
- The development of programs, resources and strategies that promote enhanced communication between formal and informal caregivers and/or facilitate formal care providers' understanding of caregivers needs
- The development and/or evaluation of peer support or volunteer supporting interventions that support caregivers including, for example, online social networks and face to face support groups
- Effectiveness of strategies and programs to support caregivers with a focus on outcomes including health status of client, health status of caregiver, client and caregiver satisfaction or experience measures and stress reduction)
- Availability, appropriateness, and/or effectiveness of supports and resources for caregivers in navigating through the health care system and their role in it
- Programs that investigate and/or address factors affecting family and client centred care engagement with health care providers from a caregiver perspective
- Programs that support the training and delivery of family and client centred health care
- Policy investigations and recommendations to address the needs of caregivers
- Best practice guidelines and recommendations for providers working with family caregivers
- Effectiveness of virtual technology to close information deficit experienced by informal caregivers (including timely access to appropriate information)
- The investigation/evaluation of the need for or benefit of respite programs for caregivers and key program elements.

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