

PATIENT ALUMNI REPORT

University of Ottawa Heart Institute



UNIVERSITY OF OTTAWA
HEART INSTITUTE
INSTITUT DE CARDIOLOGIE
DE L'UNIVERSITÉ D'OTTAWA



PATIENT ALUMNI
ASSOCIATION DES
ANCIENS PATIENTS

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PARTNERSHIP AGREEMENT

UOHI and UOHI Foundation

As a strategic partner of the University of Ottawa Heart Institute (UOHI), the Ottawa Heart Institute Alumni Inc. (Alumni) supports patients by promoting heart health and best practices in patient care, research and education.



Term of Agreement

April 1, 2016 to March 31, 2021

Date of Evaluation Report

March 31, 2019 (end of Year 3)

VALUABLE PARTNERSHIP FORGED IN 2016

In April 2016, the Ottawa Heart Institute Alumni Inc., the University of Ottawa Heart Institute, and the UOHI Foundation entered into a five-year partnership agreement through which the Alumni would receive operational and program funding in return for services it is uniquely positioned to provide.

The Alumni association provides a mutual support platform through which UOHI patients, family members, and caregivers can both receive and participate as “patient partners” and champions in developing heart health related information, education, and other services that contribute to their well-being.

The Agreement is built upon values shared by all three parties, in particular, a commitment to supporting excellence in the development and delivery of the UOHI’s research and clinical programs, thereby contributing to ongoing improvement of the patient experience and patient outcomes as part of the continuum of care.

Three years into the Agreement, the Alumni has fully achieved and continues to deliver on the Objectives set out on pages 6 and 7.

The Alumni Board of Directors and its many volunteers work side by side with patients and UOHI staff



Empower UOHI patients in their pursuit of wellness



Help the Institute be a world-class model of patient-centred care



Actively participate as part of the UOHI’s continuum of seamless services – creating a Circle of Care

A CLOSER LOOK AT THE NEW ALUMNI

The pages that follow expand upon highlights of the Alumni’s achievements under the Partnership Agreement. Specifically, these accomplishments are the very foundation of the new Alumni which, today, stands proudly beside the UOHI and the Foundation as a contributing partner.

No-fee Alumni Membership

The five-year Cooperation Agreement between the UOHI, the Foundation and the Alumni has enabled the Alumni to achieve a higher level of operation. Central to this was the establishment of a new Alumni membership model. Since 2016, discharged UOHI patients automatically become members of the Patient Alumni, at no cost. Membership is also open to patients’ family members, caregivers, and others with an interest in the UOHI and its work. Should they choose, Alumni members can opt out of membership at any time.

The Alumni is now the first point of contact with discharged patients. Patients and their families may learn about the Alumni through various means, including as part of the information they receive upon discharge. After 60 days, contact information for new Alumni members is shared by the Alumni with the Foundation, so they can be approached as prospective donors.

This is an important development in how the UOHI maintains contact with discharged patients – by establishing a community with:

- a common connection to the Heart Institute,
- interest in learning about heart health and good lifestyle choices, and
- a shared desire to contribute to the UOHI’s future success.

After implementing the new membership model, the Alumni grew from about 2,500 to more than 10,000 members. This was achieved through the mail-out of 6,500 post cards to legacy members – individuals who were in the Alumni database but were no longer “paid” members under the old membership system. Members were also added through an arrangement with myOttawaHeart – a UOHI in-house program, developed to give patients private access to their medical records. Patients registering for that service were also invited to register as Alumni members.

Growth in our membership brought with it a need to update the Alumni’s database capability. Work is now under way to move our membership data to a new, open-source Customer Relationship Management software called CiviCRM. The capabilities of the new CRM system will enable the Alumni to handle continued growth and target distribution of communications to a selected portion of members if needed, such as when conducting surveys, reaching out to volunteers, etc.



SUMMARY OF ACHIEVEMENTS

OBJECTIVE

Establish a mutual support community of UOHI patients, family members, caregivers, and others with an interest in the UOHI, through which members can share experiences as partners and obtain heart health-related information, educational opportunities, and other services.

ACHIEVEMENTS

- Alumni membership has grown from about 2,500 people in 2016 to more than 10,000 and rising by 2019.

OBJECTIVE

Align the Alumni's strategic plan and organizational activities as a strategic partner to reinforce the mandate, goals and activities of the UOHI and the Foundation.

Align Alumni communication strategies to reflect the UOHI branding.

ACHIEVEMENTS

- In March 2017, the Alumni Board approved its 2017 – 2021 Strategic Plan. The plan's goal and objectives were developed with due consideration to the document Stronger Together: Ottawa Heart Strategic Plan 2015.

OBJECTIVE

Foster opportunities for Alumni members to contribute to the UOHI's patient engagement initiatives to improve health care delivery, enhance patient experience, improve health outcomes, maintain a high level of patient satisfaction; and create an Alumni community.

ACHIEVEMENTS

- A forward-looking proposed UOHI/Alumni Patient Engagement Process developed by the Alumni in late 2015 has now been realized. Alumni members helped construct and now work side by side with UOHI staff on a patient engagement structure that today benefits the Heart Institute, its patients and their families. This work focuses on creating active and involved "patient partners" in a wide range of activities, from clinical to research to policies and procedures development.

OBJECTIVE

Foster opportunities for Alumni members to contribute to fundraising priorities of the UOHI and Foundation.

ACHIEVEMENTS

- The Patient Alumni and the UOHI Foundation are now collaborating in support of each other more than ever before. Together, the two organizations are forging stronger links through which to create and maintain lasting relationships with Alumni members who, in turn, support the UOHI with financial donations and as volunteers.



OBJECTIVE

Develop and deliver professional, bilingual resources and services that are of value to and promote the well-being of Alumni members and thereby support the interests of the UOHI and the Foundation.

ACHIEVEMENTS

- The Alumni has redesigned its web site with significant upgrades and made it more user friendly and it was re-launched in August 2019. Email newsletters are regularly distributed to Alumni members, providing news about the UOHI, upcoming special events, health information events supported by the UOHI professionals and patient partners, and nutritional heart-healthy recipes. The Alumni also contributes to the development of educational videos and print materials on UOHI patient care (examples: CSICSU pamphlet – UPP, Dr. McDonald & staff; information vide-os to help patients prepare for cardiac procedures, etc.).

OBJECTIVE

Pursue partnership opportunities through which to expand and support its services to Alumni members and/or which benefit the UOHI and the Foundation.

ACHIEVEMENTS

- Within the UOHI, the Alumni association has developed close working ties with other volunteer groups and specialized clinics, including:
 - Holding heart healthy cooking events (in collaboration with UOHI dietician and Tickers)
 - Working with the Ottawa Heart Support Group to promote and bring Alumni members to their monthly educational speaker sessions
 - Working with UOHI professional staff and communications staff to hold periodic "Meet the Expert" events on specific subjects of interest to patients (such as heart transplant, atrial fibrillation, anxiety and depression following a cardiac event)
 - Supporting activities of the in-patient support group working in conjunction with the Canadian Women's Heart Health Centre (the leader of this initiative is an Alumni Board member)
 - Meeting with UOHI patient care providers to determine what services/projects the Alumni should fund to enhance patient comfort and support
 - Assisting in the creation and delivery of focus groups on many subjects in support of the UOHI professional staff
 - Supporting/developing surveys in support of specific activities and research projects of the UOHI professional staff
 - Providing a patient perspective in the review of research project proposals
 - Participating in the UOHI's accreditation process (2017) by Accreditation Canada
- External to the UOHI, the Alumni's long history of achievements and special relationship with the UOHI have drawn significant interest from other medical institutions interested in establishing similar patient-focused groups.
- In 2018, the Health Standards Organization (HSO) recognized the Alumni-Patient Partnership as a Leading Practice – the only such organization to achieve this prestigious recognition.



PATIENT ENGAGEMENT

Giving Patients a Voice

While many health care institutions are just now beginning to enable patients to take a more active role in their own treatment and care, the UOHI established the Alumni association in 1985. The Alumni organization stands as an early model of effective patient engagement. With a more than 30-year head start, the Alumni was well prepared to work alongside the Heart Institute to explore the realm of patient engagement in the context of contemporary health care practices.

In late 2015, the Alumni developed and shared with the UOHI leadership a proposed vision for its involvement as one of several sources of input into UOHI patient engagement initiatives. By 2016, work was underway collaboratively between the UOHI staff and the Alumni to create the committees and other mechanisms through which this activity would be undertaken.

The Alumni helped develop Terms of Reference for three new UOHI committees:

- Patient Partnership Steering Committee
- Patient Engagement in Research Advisory Council (PERAC)
- UOHI Patient and Family Partnership Group (UPP)

All three committees are co-chaired by members of UOHI management and Alumni President, Jean Bilodeau.

Soon after these new committees were formally established, Alumni members were recruited to participate as patient partners in the enrichment of the UOHI's research and clinical services. Today, those volunteers continue to actively participate in the development of new approaches and programs aimed at improving the delivery and quality of care.

From there, the opportunities for Alumni members to contribute to the UOHI's patient engagement initiatives have grown (See "Annex 1: Everyone at the UOHI has a role", page 28). Alumni members are now involved in numerous committees and activities which improve health care delivery, enhance patient experience, improve health outcomes, maintain a high level of patient satisfaction, and create a more vital Alumni community. These activities have led to the creation of a formal inventory of dedicated "Patient Partners" that would/could be involved in surveys, focus groups and clinical initiatives.

The UOHI committee structure is supported by an internal UOHI structure that further demonstrates how involved the Alumni has become as a partner with the UOHI (See "Annex 2: UOHI Patient Engagement Support Structure", page 28).

The committees created a "Patient and Family Engagement Framework", now shared online so that patients and the public are aware of this UOHI policy document. It reflects the UOHI's commitment "to ensure patient and family engagement across the continuum of their experience: during their care, within the microsystem of the clinic or ward, within the organization and within the larger community."

In addition to defining the *raison d'être* for patient engagement and the roles that can be played by Patient Partners, four key outcomes are identified:



Improved Patient Experience

Active patient engagement will improve the patient experience.



Improved Patient Outcomes

Patient experience will be used to help drive better outcomes.



Better Research and Knowledge Translation

Patient and family engagement in research will be used to leverage patient experience to improve the quality and relevance of research from a patient perspective.



Improved Service Delivery

Co-designing services with patients and families will be done to provide enhanced service delivery.

Patient and family engagement is now part of an overall culture of engagement among the hospital leadership, board, researchers, staff, patients and families. Robust patient engagement is a strategic priority for both clinical care and research. This partnership is integral to quality.

Patients are actively encouraged to get involved, and Patient Partner guidelines have been developed and published online to help patients understand how they can get involved and prepare them for the work they could be involved in, working with UOHI staff: www.ottawaheart.ca/clinicalresearch

The framework as well as additional information about the scope and nature of UOHI's commitment to patient engagement is available online at: www.ottawaheart.ca/patients-visitors/patient-engagement-framework

(See also "Annex 3: Impact of Patient Engagement at the UOHI", page 29)

Patient and family engagement is now part of an overall culture of engagement among the hospital leadership, board, researchers, staff, patients and families.



The Patient Alumni is now represented on and actively engaged in the following UOHI committees:

- Co-Chair, UOHI Steering committee – Patient Engagement
- Co-Chair, UOHI Patient Partnership Council (Clinical)
- Co-Chair, Patient Engagement in Research Advisor Council (Research)
- Member, UOHI Foundation Board
- Member, Quality of Care Committee of the UOHI Board
 - Chair regular monthly focus groups with patients, family members and caregivers for input into the monthly Quality of Care Board
- Member, Research Conference Organizing/Planning Committee
- Member, MyChart/Fusion Committee
- Member, UOHI French Language Committee
- Member, Health Information Systems (HIS) Committee
- Member, Ethics Board
- Member, Change Management Committee (new tower)
- Member, UOHI President Team Spirit Award Evaluation Committee
- Member, Alumni/Research Evaluation Team of research projects for the Research Group
- Lead/Member, In-Patient Support Program - Women's Heart Health Centre

Other areas of Alumni member engagement include:

- Involvement in UOHI Tri-Board annual strategic planning session.
- Participation in the establishment of myOttawaHeart and transition to MyChart (under EPIC).
- Supporting Foundation events.
- Selection, testing and approval (on behalf of the UPP) of the patient's lounge set up and furniture for the new tower.
- Collaboration with the UOHI senior management team in Accreditation Canada's evaluation of all UOHI activities including on the issue of Patient Engagement.
- Acting as a member of the team providing patients' perspectives in the HSO development of Telehealth Health Standard.
- On an ongoing basis, providing Alumni letters of support to senior management (for surveys, studies, research projects, etc.) which in some cases leads to the award of additional funding and/or expansion of the survey or the program.
- Providing input on Alumni activities and patient engagement activities for the UOHI annual report.
- Participating in the evaluation of the Cardiac Surgery Department from the Alumni, patient engagement activities and funding point of view.
- Participation in and review of the UOHI Quality Improvement Plan

In addition, Alumni Board Members received mandatory training on Privacy, Quality & Patient Safety, etc., to ensure strict adherence to requirements for handling sensitive information.

PROJECT FUNDING

Improving Patient Comfort and Care

From its inception in 1976, the UOHI patient Alumni has been providing financial support to the UOHI to directly benefit patients with the ultimate goal of improving their comfort and providing them with services and support. The Alumni, through its Board of Directors, decide which initiatives/projects to fund, independently of the UOHI.

In the earlier years of the Alumni, the Association raised funds directly through campaign and membership fees. Those funds were used exclusively to support our main goal of improving patient comfort, services and support.

In 2016, the then CEO of the UOHI decided that, since the UOHI Foundation was being created, there should be only one fundraising organization for the Institute. The Foundation's goal was also significantly higher, as the Institute was planning a major expansion of its facilities.

With that decision, the Alumni was awarded an annual allotment of funds based on previous years' fundraising levels, to continue supporting patient-focused projects. The decision-making process on what projects, services or equipment would be funded remained solely with the Alumni, which today remains the only decision-maker on the project funding requests made by the UOHI staff.

Technical support equipment

Significant support of the Telehome wireless monitoring programs, medical telemetry for patients on the wards, video conferencing for connection and service delivery in the 14 feeder hospitals, etc.

Services

Funding for training UOHI staff, nurses, technicians, etc., patient training (i.e., CPR for patients and family members), funding for health-related training such as FrancoForme, Heart-wise exercise programs, Canadian Women's Heart Health programs, information pamphlets, rehab programs, nursing education funding, etc.

Patient comfort and support equipment and services

Meds bags, cough pillows, water bottles, vial for life, comfort bag for family, toiletries kits for patients admitted in emergency, Rise Up post surgery bra, special physiotherapy equipment, etc.

Direct patient and family support

For the past 20 years, the Alumni has provided funds to UOHI social workers. These funds directly support special circumstances of patients and family members in urgent need, such as temporary medications, financial support, temporary local accommodation for a family member, temporary transportation for a family member, special medical physical technical equipment, morale and psychological support. (See also: The Alumni by the Numbers", page 14)



OVER THE PAST 20 YEARS

it is estimated that the Alumni has spent over

\$5 MILLION

on a wide range of equipment, services and support for patients



THE FOCUS

for the Alumni is to support

PATIENTS

and family members directly

THESE EXPENDITURES INCLUDE:

Capital equipment

Fleet of beds [including critical care beds], furniture for patient/family rooms, OR tables and miscellaneous equipment, medication cart and management system, health food making/preparation equipment, etc.

Medical equipment

Patient monitoring and diagnostic equipment, cooling blankets [STEMI], sternal saws, special Operating/Anesthesia room equipment/instruments, ultrasound equipment for angiography and angioplasty, ECG, specific medical training equipment for patients [such as Motomed], specialized and regular wheelchairs, pediatric equipment, etc.

Often the medical equipment requested was for the latest technology and was often not yet funded by the Ministry of Health. This equipment was considered avant-garde, and it greatly improved patient comfort and support before OHIP funding was in place.

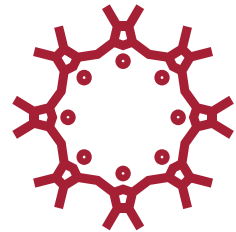
Even with the 2016 funding change the Alumni continues to independently manage patient and family support funding initiatives to this day. In the early years, a significant number of expenditures were focused on capital equipment, where it directly affected patient comfort and support. Subsequently, the focus was directed towards supporting patients and family members in other ways. For example, the Alumni funds communication tools such as our website and our CRM database whereas requestor would need to explain and justify how the requested equipment and or services would benefit directly the patients and or family members.

With the signing of the five-year agreement in 2016 between the Alumni, the UOHI and the Foundation, the decision was made that the Alumni would no longer fund any capital type equipment. The focus for the Alumni was then to support patients and family members directly. This kind of support will continue for the remaining two years of the current agreement.

A long-term project funding strategy MUST be developed for the years 2021 to 2026, to ensure the continued focus on the direct patient comfort support and services.

ALUMNI BY THE NUMBERS

Select examples of the wide impact of financial assistance provided to the UOHI for patient's support and comfort. A more detailed and comprehensive report on all projects funded by the Alumni and their impacts for the past 25 years is being prepared and will be available later this year.



500%

Increase in Alumni membership from 2000 in 2016 to 10,000+ members in 2019



10,000

Copies Alumni electronic Monthly Digest sent to members



\$5 Million +

Estimated value of more than **300** projects (including some projects valued at more than \$50,000) funded by the Alumni for patient support and comfort



1000 +

Members participating in educational information presentations to members by UOHI professionals in conjunction with the Ottawa Heart Support Group (OHSG)



50,000 +

Patients impacted by the distribution of Meds Bags, Water Bottles, Vial of Life, cough pillows, comfort bags, post surgery bras



10,000 +

Patients that have benefited by the UOHI web support through the financial support such as the Heart Wise Exercise program (implementation in 200 locations + 2,000 people trained)



5000 +

Patients, family members and/or caregivers provided financial support for special needs through the social fund (for the past 20 years)



300

CPR training sessions (21) provided to patients, family members or caregivers



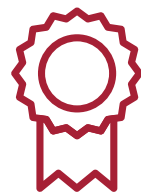
10%

Increase in donations by Alumni members to the UOHI Foundation since 2016



650 +

Female patients impacted by the women who became volunteer (13) for the Women's Heart Health bedside support program (in the first year)



100 +

Awards presented by the Alumni to UOHI staff



43,000 +

Views of the UOHI Franco Form educational videos possible through the Alumni financial support of program



460,000 +

Patients impacted by Alumni financial support for Virtual Care, floor ward Telemetry and the Rehab Center **+ 2,000 annual patients** impacted by the teleRehab connection and service delivery to 8 centers



800 +

Patient/family members participated in special training events (Meet the Experts, Health cooking events, AGM etc.)

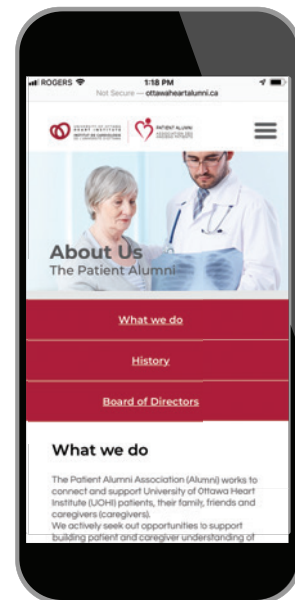
COMMUNICATIONS

Giving the Alumni a Collective Voice

Effective communication is essential to the Alumni association. With a membership of 10,000+ and growing, we need to be both creative and effective in how we reach out to our members. Our communication efforts must reflect the same compassion for patients' best interests and well-being as is a hallmark of the UOHI's care. The Alumni takes very seriously its role as an ambassador for the Ottawa Heart Institute and its Foundation.

The Alumni employs the following tools to engage with our community:

- bilingual website
- social media/online forums
- electronic/print publications
- special events/presentations



Alumni Website

Until recently, the Alumni used two web sites to reach its audience. One is a corporate web site that shares a wealth of information, such as news, links to many additional sources of information and services (including educational videos), a calendar of events, recipes and nutritional advice on heart-healthy food choices, fitness and wellness information, as well as members' personal stories.

The other was a secure Members Only community web site where patients, family members, friends and caregivers can connect to seek support and share information and experiences. This forum does not provide medical advice, but rather, is an effective tool that enables patients to contact other patients who could provide informal peer counselling.

Both sites have undergone changes. The main publicly accessible Alumni web site has undergone a redesign and has been re-launched in August 2019. The private community site, meanwhile, has been closed and will be replaced with a Facebook group (see "Social media/Online forums", page 17).

Social Media/Online Forums

Encompassed within the above is a growing need and capability for the Alumni to establish and maintain an effective social media presence. Effective use of social media platforms is just one of many ways to raise awareness and visibility of the Alumni and share important information and links to our web sites, events, etc.

Emphasis is focused on Facebook and Twitter. The Alumni has already established a Facebook page with hundred's of followers. In addition to using Facebook to share regular posts with our members, we have also used the Facebook Live feature to broadcast Alumni special events to those unable to attend in person.

As noted in the preceding section ("see Alumni Website", page 16), the Alumni is exploring use of private Facebook Groups to replace its previous members-only community website. The plan is to create sub-groups for sharing experiences and discussion on specific topics. Using a more familiar medium (Facebook) should more readily enable participation from the Alumni membership. These groups will help support specific (non-medical) needs of patients, family members and caregivers by giving them access to people who have had experience living with and obtaining treatment for specific cardiac issues.

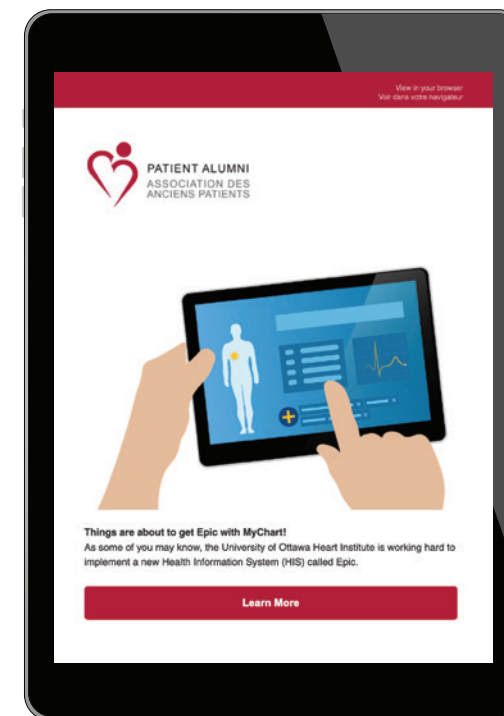
The Alumni's Twitter account is coming soon! Like our Facebook posts, "Tweets" will be regularly sent out to notify members of events and other relevant information. Over time, we expect to build a much stronger social media presence and following, with a high level of engagement and interactivity from our members.



uohipatientalumni



COMING SOON!



Electronic/Print Publications

The Alumni distributes a monthly electronic newsletter to all members, providing news about the UOHI, upcoming special events, heart health information sessions and recipes promoting heart-healthy cooking, etc. The Alumni also contributes to the development of educational videos and print materials on UOHI patient care (e.g.; CSICSU pamphlet to prepare families on what to expect when they see their family member post-surgery, information videos to help patients prepare for cardiac procedures, etc.).

An information pamphlet introducing patients and family members to the Alumni, its role, and explaining that membership is free of charge, was developed and is now distributed to all in-patients as part of the Meds bag they receive upon discharge, which also contains information on post-discharge self-care, Vial of Life, etc..

Targeted correspondence is occasionally mailed to members on an as-needed basis. In addition, the Alumni occasionally contributes articles to the UOHI online journal, "The Beat" and frequently publicizes articles from the publication in its e-newsletter and other communications to members.

Special Events and Presentations

The Patient Alumni also now holds numerous events each year. Whereas our one annual event used to be the Annual general Meeting and Awards event, we are now involved in a much wider range of activities that bring Alumni members together to learn and to socialize.

One series of such events are the periodic “Put Your Heart into Tickers” cooking sessions. With the support of Marek Hospitality (owner of Tickers Restaurant), cooking demonstrations are provided to share heart-healthy recipes with Alumni members, along with advice from the Heart Institute’s Registered Dietician. These events have been very well attended and provide a means for the Alumni association and its volunteer leaders to engage directly with members.

Other events include our new “Meet the Expert” speaker series, featuring UOHI doctors and other professional staff who make presentation on specific subjects of interest to patients (such as heart transplant, atrial fibrillation, anxiety and depression following a cardiac event). Working with the UOHI professional staff and communications staff these periodic sessions are organized at local eateries, where members can socialize and interact with the speaker and with Alumni volunteers following the presentation.

The Alumni works in close cooperation with the Ottawa Heart Support Group to promote and bring Alumni members to their monthly educational sessions for heart patients and family members, featuring presentations by UOHI medical experts on a range of cardiac conditions, their diagnosis, and treatment.

The Alumni also engages in and in some cases provides project funding support for other events. These include special events organized to champion the work of various clinics within the UOHI, supported by patient partner volunteers, such as the Women’s Heart Health Centre, the Rehab Centre, classes to teach CPR to families of cardiac patients, and focus group activities referred to elsewhere in this report (seeking patients’ input into UOHI patient care and research related procedures and practices).



The Alumni is run by the patients/family members, for the patients/family members.

GOVERNANCE

Formalization of the Alumni Organization

Good governance and accountability are cross-cutting functions that are essential to all non-profits associations and bear upon every aspect of the Alumni’s activities. As its membership has grown in recent years, so too has the need for the Alumni to update and formalize certain aspects of its operations. This ensures it is abiding by applicable legislation governing non-profits, to develop and strengthen its policies and procedures, and to establish a basis for succession and transition as volunteer positions change hands over time.

Unlike most patient advisory groups, the Alumni is run by the patients/family members, for the patients/family members. It is an independent, incorporated organization with its own operating budget. The Alumni board sets the organization’s direction and decide which initiatives the Alumni will fund and support.

New Ontario legislation governing non-profits

The Ottawa Heart Institute Alumni Inc. is provincially incorporated as a not-for-profit organization under the Corporations Act (Ontario). In 2010, new legislation was passed governing non-profits in the province, which was supposed to come into force in July 2013. Enacting the legislation has taken much longer, however, and the new Not-for-Profit Corporations Act (ONCA), 2010 is now expected to effect in early 2020. Once the legislation takes effect, non-profit organizations will have a five-year window in which to bring their governance documents into conformity with the ONCA.

The Alumni has taken a proactive approach to this change in legislation, by undertaking a review and revision of its Bylaws in 2015/2016. The Bylaws were amended to reflect recent changes in the organization, in addition to bringing them in line with the new regulatory requirements.

Work on the Bylaws was subsequently put on hold while the Alumni awaits enactment of the new legislation. Whenever the Act takes effect, a final review will be done to ensure the amended Bylaws remain in compliance with the new legislation and can subsequently be submitted approval by membership vote at an upcoming Annual General Meeting.



Greater focus on strategic planning activities

In March 2017, the Alumni Board approved its 2017 – 2021 Strategic Plan. The plan’s goals and objectives were developed with due consideration to the UOHI document “Stronger Together: Ottawa Heart Strategic Plan 2015”. Given the rapid pace of activity and changes within the Alumni association, a strategic planning retreat was held May 2019, to review and update the Alumni’s focus and direction, gauge operational and program needs, and guide decision-making and the allocation of Alumni resources in the years ahead.

Improvements to documentation & technology

The Patient Alumni Board is comprised of former patients/family members who, in most cases, bring to their volunteer role significant senior management experience from a diverse range of professional backgrounds, including from government, the private sector and non-profit organizations.

Good governance practices include documenting policies, procedures and other guidelines necessary for clear delegation of duties and authority, and succession of responsibility as turnover of volunteers occurs, especially in Executive and Board positions.

In late 2018, job descriptions were approved by the Alumni Board for the following positions:

- Alumni President
- Alumni Vice President
- Alumni Treasurer
- Alumni Directors
- Executive Administrative Assistant

The Alumni has also taken steps to improve its administration by:

- purchasing new office computers
- acquiring new financial software
- switching to a new Customer Relationship Management (CRM) software
- increasing training and use of volunteers to support the office work (including historical documentation and record management of the Alumni’s 40 years of work)

The Alumni association has an office within the Heart Institute, which is now permanently staffed; enabling staff, volunteers and the Alumni leadership to maintain close collaboration with the hospital’s staff and fundraising Foundation.



*Leading Practice
Organization Alumni-
Patient Partnership*

RECOGNITION

Leading Practice Organization – Alumni

The University of Ottawa Heart Institute (UOHI) has a rich history of patient engagement that has spanned decades. The Alumni’s raison d’être is to support patients by promoting heart health and best practices in patient care, research and education. The Alumni definition of patients includes, family members, friends, relatives and caregivers. Validation of the Patient Alumni’s hard work and many achievements come in many forms, such as:

- gratitude expressed by patients, their families and caregivers for the support provide by the Alumni and its programs;
- acknowledgement from the UOHI and Foundation leadership of the Alumni’s valued contributions as a strategic partner in improving patients’ comfort, care and experience;
- the willing support and collaboration of UOHI doctors and staff in supporting the Alumni’s activities;
- agreement by other parties to collaborate with the Alumni on special events (e.g., Tickers, Ottawa Heart Support Group, etc.).

In May 2018, the Alumni received a special validation of its efforts through formal certification by the Health Standards Organization of Accreditation Canada as a “Leading Practice Organization Alumni-Patient Partnership”. The UOHI Alumni is the first and, to date, only organization of its kind to receive this recognition. This is an especially significant achievement, not only providing important recognition of the work the Alumni performs, but also reflecting positively on the UOHI and Foundation for their vision, support and collaboration in helping the Alumni grow and thrive. Their support has been vital to our success by helping at an important juncture to shape “the new Alumni”.

The Alumni has demonstrated its importance as an important strategic partner of the UOHI, sitting on senior management boards and committees, initiating patient- and family-centered programs, and participating in numerous committees and meetings to provide input on operational and policy development, applications and quality improvement. The Alumni’s work includes reviewing policies, reviewing research protocols, and participating in quality improvement plan preparation and quality improvement projects. Alumni engagement occurs at all levels of the organization, from the support, medical, scientific, and research staff, through all levels of senior management, including the VPs and the CEO and President.

Approved by Health Standard Association (HSO), Accreditation Canada

The following table outlines the results of the HSO review of the Alumni as a Leading Practice Organization:

CRITERION	REVIEWERS' COMMENTS
Innovative/ Transformative	<p>At the time that this organization was created, it was truly innovative in its mandate as a patient-driven driver of quality improvement among other objectives. Today, there are other organizations that are patient/family run, that have equally strong mandates. Having said that, the historic innovativeness and current longevity of the Alumni is to be lauded.</p> <p>Research on health care innovations indicate some primary metrics including consumer (patients) participation, utilization of technology to advance and improve care services and development of new operational models for integration of separate dimensions of health care. The submission about the Alumni –Patient Partnership exemplify these innovative measures.</p>
People-Centred Care	<p>The true hard-wiring of patient-centeredness from governance structures to research priorities, operations, to providing services to patients, is impressive.</p> <p>In its report on Patient-Centred Healthcare Initiatives (WHO Western Pacific Region 2010), WHO identifies four domains of patients and communities, health practitioners, healthcare organizations and health systems and calls for an operations and policy framework which considers all components as parts of an integrated system. The positive achievements of the Alumni Patient Partnership as described in the submission resonate with the WHO principles.</p>
Evaluation Methodology	<p>The proposal outlines how the Alumni evaluate membership satisfaction, but there is no evaluation approach provided to assess the effectiveness of the Alumni in achieving their mandate in terms of patient or community outcomes. In fact, the mandates or objectives of the Alumni are not clearly articulated beyond, essentially, a vision statement.</p>
Demonstrated Intended Results	<p>Literature review indicates that in today's healthcare environment, meaningful patient engagement is achieved with supportive organizational vision, buy-in from front-line providers and staff and right tools and technology. The Alumni Patient Partnership seems to provide an efficient model for this in terms of both its intent and demonstrated results.</p>
Adaptability to Other Organizations	<p>Research studies demonstrate that successful adaptation of patient engagement projects in healthcare generally depend primarily on organizational vision for patient engagement, creation of a culture of engagement, employment of right technology and services, empowerment of patients as collaborators in their own care and focus on transformative results. Patient Alumni Partnership project of the UOHI is "fit for this purpose."</p>

FULFILLING THE REMAINDER OF THE CURRENT AGREEMENT

Outlook for 2019/20 and 2020/21

The Alumni takes great pride in its achievements over the past three years, and enthusiastically looks ahead to the valuable contributions it will continue to make during the remaining two years of the current partnership agreement (ending March 31, 2021). In addition to carrying on as a vital strategic partner of the University of Ottawa Heart Institute (UOHI) and its Foundation, the Ottawa Heart Institute Alumni Inc. (Alumni) is deeply committed to supporting patients by promoting heart health and best practices in patient care, research and education.

As the agreement enters its last two years, certain provisions will come into play:

- **7.9:** The parties agree to review the financial allocation (in accordance to the financials in section 7.2) to the Alumni during Year 3 (Apr. 1, 2018 to Mar. 31, 2019) to determine if the funding provided remains sufficient to achieve the parties' mutual objectives. Any amendment to the amount of funding provided for the remaining term of the agreement (April 1, 2019 through March 31, 2021) shall take effect the beginning of Year 4 (Apr. 1, 2019).
- **7.2:** The parties agree to the following funding allocation schedule, which provides revenue required by the Alumni for its operating and program activities associated with delivering the services identified in this agreement.

	ALUMNI FISCAL YEAR	PROPOSED ALLOCATION FROM THE FOUNDATION	
		OPERATIONAL FUNDS	PROGRAM FUNDS
Year 1	Jan. 1, 2016 to Dec. 31, 2016	\$100,000	\$150,000
Year 2	Jan. 1, 2017 to Dec. 31, 2017	\$100,000	\$150,000
Year 3	Jan. 1, 2018 to Dec. 31, 2018	\$100,000	\$150,000
Year 4	Jan. 1, 2019 to Dec. 31, 2019	(status quo, unless otherwise determined as per paragraph 7.9)	
Year 5	Jan. 1, 2020 to Dec. 31, 2020	(as decided & implemented effective Year 4)	

- **4.4:** The parties shall, during Year 5 (April 1, 2020 to March 31, 2021) discuss renewal of the agreement, the process for which shall involve:
 - **4.4.1:** a review of achievements to date as a result of the agreement;
 - **4.4.2:** identification by the parties of the goals/objectives they would like to achieve in the next five years;
 - **4.4.3:** development and review by the Alumni of its forecasted financial and in-kind requirements required to sustain its operations and achieve the identified objectives for the next five-year period (April 1, 2021 to March 31, 2026); and
 - **4.4.4:** acceptance by the parties of a new (or amended) agreement modelled upon paragraphs 4.4.1 to 4.4.3.

The Alumni has not requested any increase in its funding for 2019/20 or 2020/21. Growth in the Alumni membership and its operations (to support a larger community of members) will be an important factor influencing our activities throughout the duration of the current agreement. However, the Alumni recognizes the other financial demands on the UOHI arising from the construction of the new tower and associated equipment costs.

OUR PRESENT

For 2019-2021, The Alumni will:

Remain focused on current objectives and continue to actively support our members.

Over the next two years, it is projected another 5,000 to 10,000 new members may join the Alumni, adding to our current membership of 10,000+ patients, family members and caregivers. The Alumni will continue to seek efficiencies where required to offset the increased costs of providing an expanded level of service to a growing membership.

Expand and further develop the Patient Engagement work started in 2015.

As the pace of activity continues to escalate, we expect Alumni members will become increasingly involved as patient partners, supporting the UOHI's research and clinical through surveys, focus groups, and representation and activity on many committees. (See the section: "Patient Engagement: Giving Patients a Voice".)

Continue and increase its project funding activities.

Requests seeking Alumni project funding to improve patient care have declined in recent years in part, we believe, because the Alumni has been focused on organizational growth. Underspent funds from previous years remain available to support projects that enhance patient care, comfort and support. The Alumni will work to increase funding requests through outreach to UOHI staff who work directly with patients. In addition, as we look for new ways to support patients and family members, consideration may be given to projects that expand our reach and enable communication with our diverse membership, sharing information that directly benefits patients and family members.

Finalize and stabilize its revamped web site and its new Facebook presence.

Through the boundless commitment and persistence of its volunteers, the Alumni has gotten much better at communicating with its members. (See the section: "Communications: Giving the Alumni a Collective Voice".) As the community grows, so too does the need keep our members connected with the Alumni association, the UOHI and the Foundation, through a variety of means. Over the next two years, we expect to sustain and increase our current communications activities, including enhancing our profile on social media, through increased use of Facebook, by creating an Alumni Twitter page, and issuing more frequent posts through both Facebook and Twitter.

Continue and strengthen its support activities to the Foundation.

The Alumni Board and volunteers will continue to work in collaboration with the Foundation to share information, including new Alumni membership information (after a 60-day waiting period), to help build its donor list and increase donations – an essential part of the UOHI's funding regime.



OUR FUTURE

Extend its long-term strategy outlook, from 2021 to 2026:

The Alumni's current strategic plan covers the years 2017 through 2021, the same term as the trilateral partnership agreement. Looking ahead, the Alumni will begin considering what comes next and will be paying special attention to the 5-year strategy being developed by the UOHI for the same period (expected to be completed by the fall of 2019).

The Alumni Board is in full agreement with the following direction for the remaining term of our existing partnership agreement (until March 2021) and looking ahead into the next 5 years. The Alumni plans to:

1. Change the leadership role of the Alumni to a role of incubator as patient centered development;
2. Consider and integrate Patient Engagement of caregivers, members, family, which align with the UOHI's Heart Team concept and the "hub and spoke" concept;
3. Evolve the role of the Alumni within primary and secondary prevention;
4. Promote/share model of the Alumni concept through dissemination;
5. Develop the Hub and Spoke concept within the patient community through participation, testing, pilot projects, etc.;
6. Enhance the role of the Alumni as a strategic partner of the UOHI through anchoring the Alumni as a separately incorporated but integrated part of the UOHI organization structure;
7. Evolve the Alumni organizational framework to respond to needs to:
 - Support the UOHI strategic plan;
 - Ensure sustainable funding for operations and patient projects;
 - Develop a human resources plan for paid resources and volunteer;
 - Enhance governance structure through:
 - Its mission, and its composition
 - Its constitution bylaws
 - Policies and procedures

The above actions are proposed for consideration by and discussion with the UOHI. They acknowledge the Alumni's unique accreditation by HSO as a Patient-Centered Leading Practice Organization, and the attractiveness of the Alumni a patient engagement model adaptable by other health care institutions. With its proven track record over the past many years, the Alumni is well positioned to help the UOHI achieve its goal of becoming a world renowned Heart Institute.

Connecting and supporting the UOHI patients, their family, friends and caregivers



A Brief History of the Ottawa Heart Institute's Patient Alumni Association

The University of Ottawa Heart Institute (UOHI) is Canada's largest and foremost cardiovascular health centre, seeing more than 200,000 patients a year. With its seeds planted in the mid-1970s, UOHI's Patient Alumni Association is likely Canada's, and possibly the world's, first-ever patient engagement program.

How It Began

In 1976, the Head of Physiotherapy at the brand-new UOHI felt it was essential for patients to stay involved with the Institute following surgery. At the time, the Institute's surgical program was made up of just four beds. The Head of Physiotherapy instituted a rehab program, with patients attending twice a week for six months following surgery; as many as 400 patients came through the rehab program at its inception.

In 1985, the Patient Alumni Association "Alumni" was officially created as a legal entity. The first thing the Alumni did was to ensure that all surgical patients received a letter inviting them to become members. Members received ongoing education and support, and in return many members contributed to an Association fund, of which 100% of the proceeds were spent on improving patient comfort and support.

The UOHI Patient Alumni Association evolution over the years

Since its inception, the Alumni has had more than 12,000 former patients as active members. The Patient Alumni Association functions as an incorporated charitable organization with a Constitution and a Board of Directors to guide its activities. Membership is open to all UOHI patients, former patients and their relatives, friends and caregivers. In the past, members paid a nominal annual membership fee. However, the Association recently moved to a new membership model whereby all patients automatically become members of the UOHI family, with no membership fee required.

The UOHI Patient Alumni Association today

The Alumni has become a key strategic partner of the University of Ottawa Heart Institute, through its important work on Patient Engagement in recent years, in addition to ongoing work in many other areas. One of the Institute's main strategic visions is to be a world class patient-centred heart institute in Canada.

Another significant partner of the Alumni is the UOHI's Foundation. The Alumni works very closely with the Foundation through a funding agreement with the UOHI and in its direct fund-raising efforts.

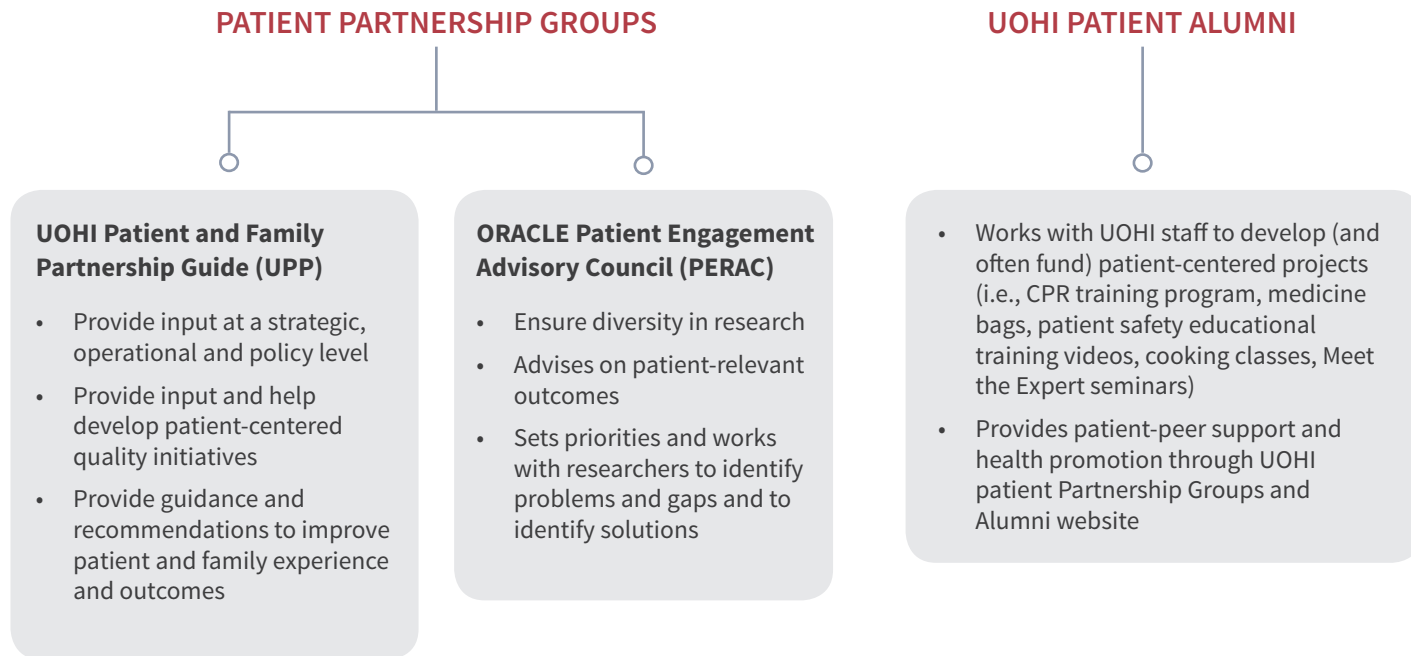
Over the years since its inception, the Alumni has always maintained its original *raison d'être*: "Connecting and supporting the UOHI patients, their family, friends and caregivers".

The engagement of patients (Alumni members) has been the key focus of activities of the organization through a significant number of initiatives that involve members in practically all aspects of running and managing the UOHI. For example, Alumni Board members (including patients and family members) are members (participant, co-chair or chair) of almost 20 committees/boards/working groups/regular meetings of the UOHI. Their input is sought on policies, procedures, quality of care of patients, research activities, evaluation of services, focus groups seeking input from patients and family members, etc.

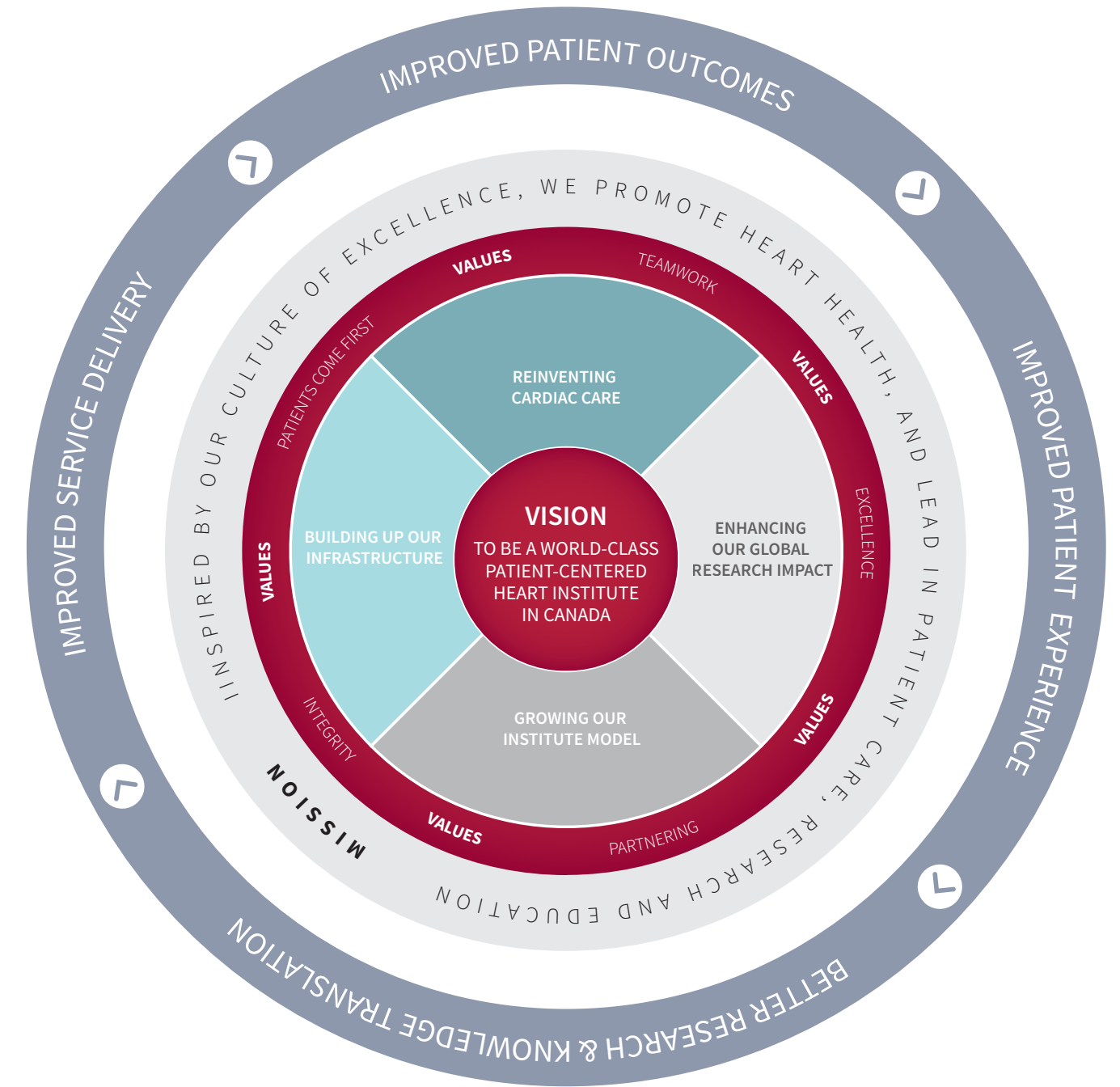
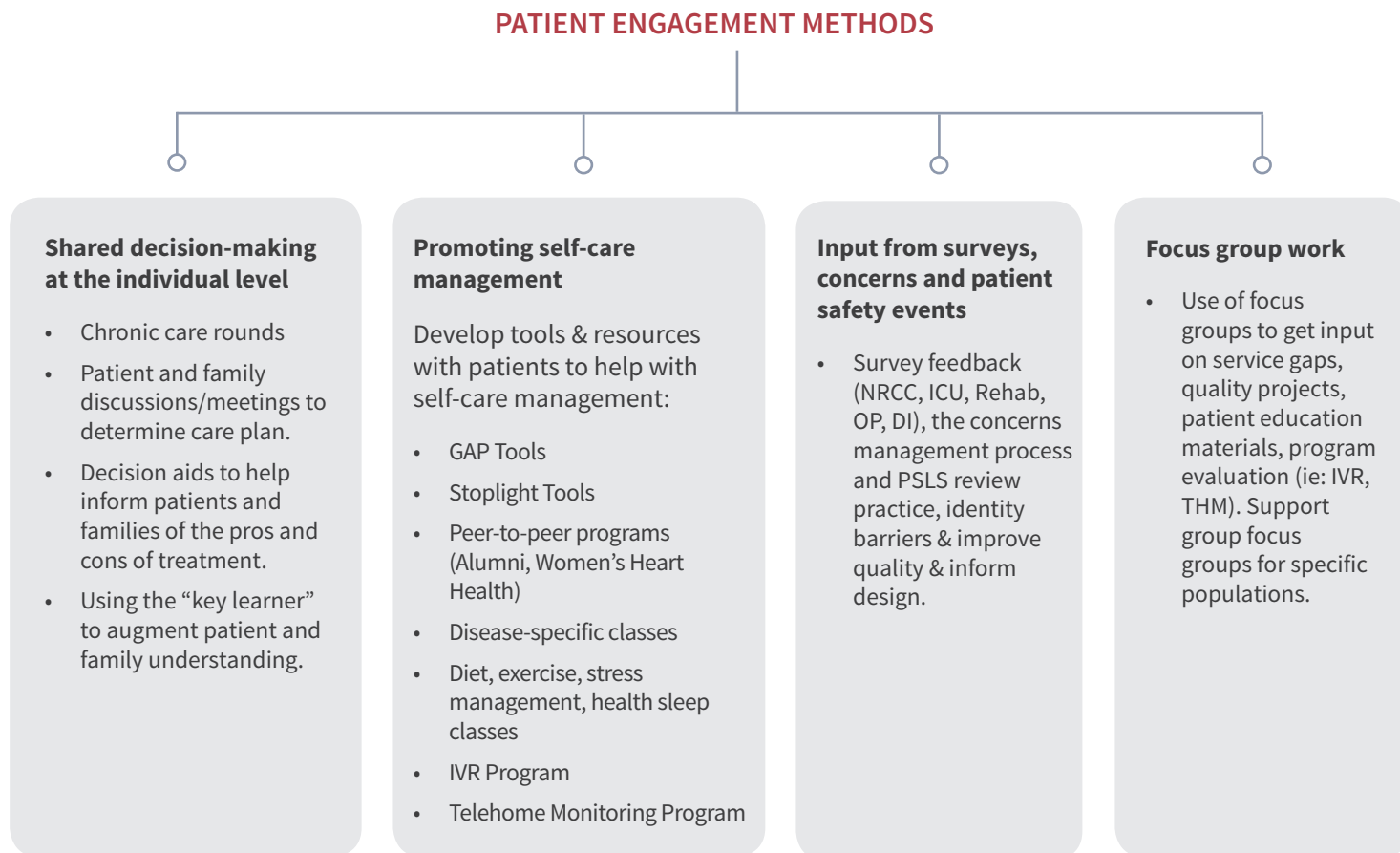
The Alumni also delivers activities and services directly to members for the benefit of patients and family members while at the UOHI and after their stays/visits. These activities include improvements to patient care through training, education and practical advice, patient-focused videos, and support for enhanced services and medical/scientific equipment.

The members of the Alumni are very engaged in its activities and communications. Most of the communications are done electronically through Alumni web sites (Corporate and Community Forum), emails, monthly digests, etc. The "click open rate" of the electronic communications produced by the Alumni is at 40-45%, which implies a very engaged community (industry standard is 15 to 18%).

Over the past several years the Alumni has funded the acquisition of scientific and medical equipment out of its own budget, as well as a variety of support services directly related to patient comfort and support. Well in excess of five million dollars has been spent by the Alumni to fund these initiatives.



ANNEX 2 • UOHI PATIENT ENGAGEMENT SUPPORT STRUCTURE



The UOHI, the Patient Alumni and the Foundation are now collaborating through a trilateral partnership that supports the UOHI Strategic Plan and Circle of Care.

ACKNOWLEDGEMENTS

In closing, this report would be amiss if it did not duly recognize the players and the organizations that have had a tremendous bearing on the success of the Alumni. They include:

- UOHI founder, the late Dr. Wilbert Keon, whose vision led to the creation of the Alumni;
- Mary Clinckett who founded the Patient Alumni organization;
- UOHI President and CEO, Dr. Thierry Mesana, whose vision and steadfast support are carrying the Alumni to the next level,
- UOHI Foundation CEO, Jim Orban, whose support for and collaboration with the Alumni are deeply appreciated, and the
- UOHI management team and the innumerable doctors, nurses and staff who work closely with and support the Alumni.

Heartfelt gratitude is also extended to long-standing Alumni President Jean Bilodeau and the Alumni Board of Directors, for their vision, commitment and leadership. And we thank the many members who serve as Alumni volunteers, and the volunteers of other UOHI groups with whom the Alumni cooperates:

- Ottawa Heart Support Group;
- Women's Heart Health;
- Heart Institute Auxiliary.

For the Alumni, the past three years are evidence of the wisdom of those words. What we have succeeded in doing has only been possible through a coalescence of like-minded people with a common desire to serve the best interests of UOHI patients, contribute to their improved heart health, and facilitate their contributions to the future success and sustainability of a world-class and world-renowned University of Ottawa Heart Institute.

“Coming together is a beginning, staying together is progress, and working together is success.”

- Henry Ford



LIST OF PATIENT ALUMNI BOARD MEMBERS SINCE 2015

- Anne Auger
- Jean Bilodeau
- Steven Brasier
- David Brisco
- Carolyn Cooper
- Daniel Giasson
- Ann-Marie Julien
- Berny Latreille
- Nancy Lawson
- Richard Lindo
- Marion Martell
- Brian Moore
- Elizabeth Murphy-Walsh
- Andre Pascal
- Angela Peterson
- Steve Sharp
- Anne Stolarik
- Stephen Stuart
- Fay Turner CAO
- Angela Verebes-Budge EA/COA

FOR MORE INFORMATION

Despite its comprehensiveness, this report has only scratched the surface of the Alumni's scope of involvement in the various areas of activity outlined.

The Ottawa Heart Institute Alumni Inc. would be pleased to provide additional information to anyone wishing to learn more about any of the topics covered within this report. To learn more, please contact:

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