

# Putting Patients at the Heart Co-design Design Briefs

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PPATH Healing Hearts Learning Program

# The PPATH Healing Hearts Learning Program

## Co-design with Patients, Caregivers and Staff

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### **Background**

In February 2017, Trillium Health Partners and Saint Elizabeth invited the Saint Elizabeth Research Centre to co-design improvements to the patient experience in the PPATH (Putting Patients at the Heart) Cardiac Program, a joint program of Trillium Health Partners and Saint Elizabeth. Acknowledging that the clinical outcomes of the PPATH program have been excellent, there were some indications in the patient surveys that suggested the program could do even better if patient experience could be improved. Together, the Saint Elizabeth Research Centre began a co-design process working with patients, caregivers and staff from Trillium Health Partners and Saint Elizabeth to better understand the core challenges related to the patient and caregiver experience and to develop ideas together to address those challenges.

### **The Co-design Process: Kick-off Workshop**

The process began with an exploratory workshop in March 2017 which invited a broad group of patients and caregivers from the PPATH program as well as clinical staff, administration staff and leadership from both Trillium Health Partners and Saint Elizabeth Health Care. Participants used patient personas and narratives to create an empathy map across the cardiac experience and then identified key moments where better support was needed.

Six themes describing challenge areas emerged from the March session that became the foundation for the next phases of the project.

### ***Fear of the Unknown***

Patients and caregivers expressed a sense of being overwhelmed across the cardiac experience, which included fear and/or anxiety for both.

### ***Information Overload***

The amount of information received by patients was identified as being overwhelming. Patients and caregivers agreed getting 'the right information at the right time' was important.

### ***What is Going to Happen?***

It was not always clear to patients and caregivers how the whole PPATH program worked, from hospital to home, including number of visits, questions about rehab and how the program ended at 30 days.

### ***The Family Physician***

Patients and caregivers expressed a lack of clarity about, if and when, they should speak with their family doctor about their PPATH experience. There were also a range of experiences with family doctors, from positive to negative, after surgery. Participants generally agreed that messaging about how to engage their family doctors was inconsistent.

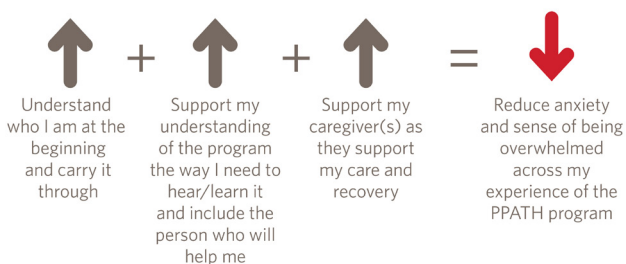
### ***Caregiver Worry***

Family caregivers expressed the feeling of being 'out of the loop' and/or feeling ignored, while also experiencing anxiety and worry. These feelings were linked to a lack of education and lack of communication. Caregivers expressed the need to juggle existing and new responsibilities and that sometimes distance was a factor.

### ***One Size Does Not Fit All***

Patients and caregivers expressed that everyone is different and that there needed to be opportunity for clinicians and staff to ‘understand who I am’ in both the hospital and home setting.

The following diagram illustrates the relationship between the themes that emerged from the exploratory workshop and was the foundation for further work.



### ***Co-design Workshop Series***

To further explore the themes\* from the March workshop, and focus on specific touchpoints, we invited patients, caregivers and staff to attend one of three co-design sessions throughout the month of June 2017. Participants identified what information they wanted to know, at what point in the PPATH experience and how they would like to learn that information. They also imagined possible new tools to support their learning. Ideas from each session were shared in the session that followed and developed further.

A set of key principles, and concepts for information sharing tools, emerged from these co-design sessions.

### ***Key Principles***

#### ***The Earlier the Better***

There was strong agreement that information — all of the information — needed to be shared as early as possible. This acknowledges that patients have different experiences, and that not everyone wants the same information. However, the ability to have information available and to search for what they need in advance of arriving at the hospital for surgery was highly desired.

#### ***Patients and Caregivers want Different Information at Different Times***

A clear theme from the co-design series was that the information patients are seeking, and when they seek it, is different than what their caregivers are seeking and when they seek it. For example, patients may want information about the surgery itself early, but not want to know details about the whole experience. On the other hand, caregivers consistently indicated they wanted to see the full picture, including what is required after surgery, once they are home.

#### ***Timing of Education, and Information Sharing, is Important***

Directly related to information seeking, patients and caregivers indicated that when they receive information, it is connected to how much information is retained. For example, when a patient is in surgery, a caregiver is only concerned about what is going to happen in the next 24 hours. They are focused on if the patient will survive the surgery and then when they will be able to see them. Learning, and retention, during this time frame is not optimal.

\* In discussion with the PPATH steering committee, it was decided that the relationship between the program and family physicians was not within the scope of this project, and so more work was initiated by the Research Centre members. However, the transition of care from the PPATH program to the family doctor continued to be raised through the next phases of the project. For this reason, it is recommended that the connection between the program and family doctors be pursued by Trillium Health Partners and Saint Elizabeth.

### ***Education Needs to be Consistent across Channels***

Both patients and caregivers are open to different ways of learning such as in-person (discharge class), printed material (HEART brochure) and digital (videos and website/app). It is important that there is consistency between learning channels and that the connection between them is explicit so patients and caregivers are able to access each way of learning when they choose. For example, if a caregiver is not able to attend a discharge class, the same information must be available through printed material and digital channels such as video and a website/mobile app.

### ***Caregivers Need Much More Support — that Speaks to Them***

Caregivers expressed that they feel a heavy weight of responsibility in the care and recovery of patients after surgery and that they feel completely unprepared for that responsibility. Once they are home, they are nurse, physiotherapist, dietitian, motivator, etc. and believe they need to 'get it right.' They want information and support early and want to know how to plan and prepare to juggle their current responsibilities such as taking time off work, planning for meals and ordering the right equipment. Caregivers also indicated that they needed support to know how to provide motivation (encourage/limit) for exercise and activity as well as how to identify when something connected to the recovery from surgery is 'not normal.'

Caregivers said they could use new tools that speak directly to them and better prepare them for what they will be expected to do. It is also important to note that patients are aware that their caregivers are taking on this responsibility and rely on them once at home. Patients are very focused on their own feelings and state of being after surgery and trust that their caregivers will have a handle on everything else.

### ***Transition Out of PPATH is Abrupt***

Both patients and caregivers indicated the program 'just ended'. This was also true for patients who were only accessing the hotline and not receiving additional home visits as part of the 30 day post-hospital support.

The *Putting Patients at the Heart Touchpoints and Empathy Map* document, included in this package, illustrates the themes noted above.

### ***A Note about Language***

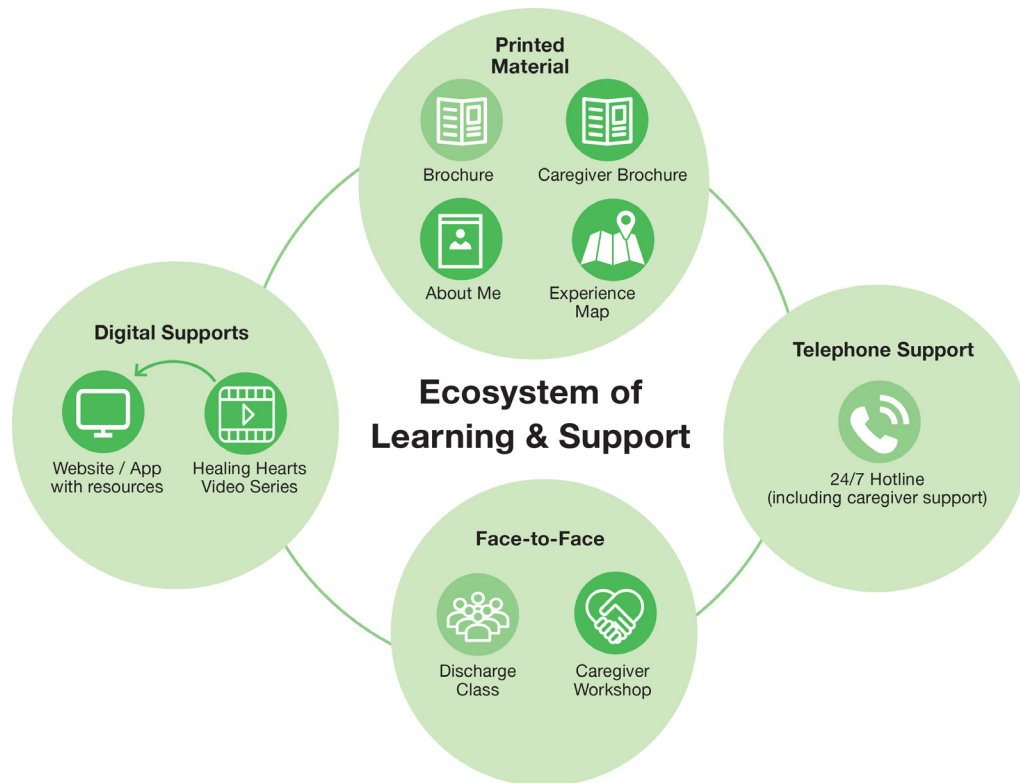
In the first session of the co-design series, patients strongly offered the perspective that referring to cardiac surgery as 'elective' and 'urgent' did not make sense to them, particularly for those categorized as 'elective.' Even though patients in this category had scheduled surgeries they did not consider them to be a choice and therefore they did not 'elect' to have cardiac surgery. As such, the Research Centre project team revised the language to 'Planned' and 'Unplanned' and these terms were used for the duration of the project and are used throughout the attached documents.

### ***The PPATH Healing Hearts Learning program***

Taking into account the themes from both the exploratory workshop and the co-design workshop series, an ecosystem of learning and support was developed incorporating four different approaches to providing learning, including:

- Printed material (HEART Brochure, Caregiver Brochure, PPATH Experience Map, About Me pages)
- Face-to-Face (Discharge Class, Caregiver Workshop)
- Digital Support (Videos Series, Website/App with resources)
- Telephone Support (24/7 Hotline)

The learning program builds on existing learning tools available to PPATH patients and supplements those tools with ideas that emerged from the co-design sessions, such as a caregiver brochure, a video series and a website/mobile app.



The diagram above illustrates the initial concept of the learning program.

### Exploring the Learning Program through a World Café

On September 13, 2017, the Research Centre project team invited participants, including those that attended any of the previous co-design sessions, to attend a World Café-style<sup>1</sup> afternoon to explore each of the elements in the learning program. Over 40 people attended the event, including patients, caregivers, Trillium and Saint Elizabeth staff and leadership to collaborate on idea refinement, and provide feedback, through a series of collaborative activities. The goal was to further develop the details of each learning tool, including timing and experience, and to inform the creation of a fully formed prototype and piloting. An exploratory prototype of one of the

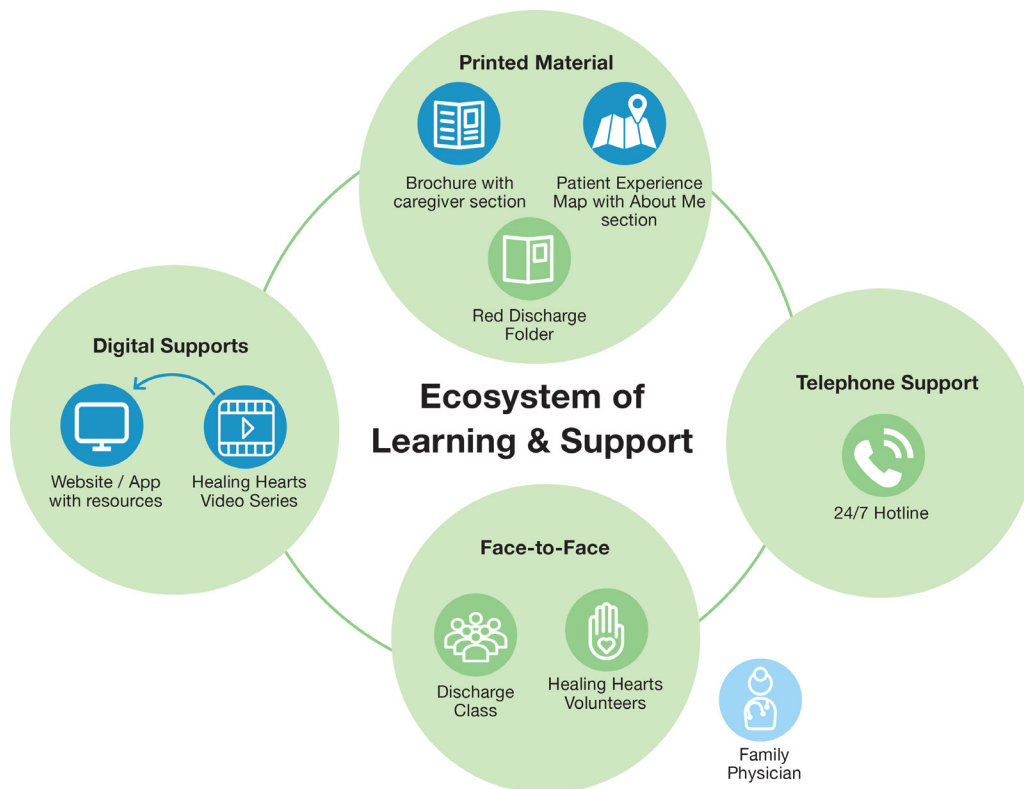
ideas — the PPATH Experience Map — was used as a guide to activities at each of four tables including printed materials, online learning, in-person learning and transitions and the family doctor.

Synthesis of the feedback and contributions shared during the World Café event culminated in a smaller set of design ideas, including:

- Patient Experience Map with About Me pages
- *Patient and Caregiver Heart Surgery Education & Recovery Tips* brochure
- Healing Hearts Video Series
- Discharge Class: Preparing to go Home
- Healing Hearts Website and Mobile App

The diagram on the following page illustrates the revised learning program components.

<sup>1</sup> World Cafe Method. (2017). The World Cafe. Retrieved 7 July 2017, from <http://www.theworldcafe.com/key-concepts-resources/world-cafe-method/>



### The Red Discharge Folder

Patients currently receive a red folder at discharge from Trillium Hospital which contains information about the PPATH program and how to seek medical care after surgery including the 24/7 hotline number; a letter to the primary practitioner; a consent form to participate in the patient survey; specific information about patients' discharge such as medical orders; and a medication schedule. Although the red discharge folder has not been re-designed as part of the learning program, it should be leveraged as a tool to share information about some of the components in the learning program.

### Healing Hearts Volunteers

The PPATH program currently has a group of dedicated volunteers who have had cardiac surgery. They give their time in the hospital to speak with patients and families who are currently having surgery. Healing Hearts Volunteers might meet families while they are in the waiting room during surgery, offer their experience in the discharge class or meet with patients

on the unit. Throughout the co-design sessions, patients and families said that hearing the personal experiences of the volunteers was very helpful and they valued being able to speak with someone who had recovered from cardiac surgery. The role of the Healing Hearts Volunteer has not been re-defined as part of the eco-system; however, this role should be leveraged as a way to share information about components in the learning program.

### The 24/7 Hotline

Patients and caregivers consistently indicated that they valued access to the 24/7 hotline. Caregivers in particular took great comfort in being able to call the hotline if they had a question or if they thought there was a potential problem. Both patients and caregivers indicated that, ideally, the hotline would be extended beyond 30 days, and that there is a significant gap between the end of the PPATH program and access to cardiac rehab. However, if it is not feasible to extend access to the 24/7 hotline, two areas should be explored to support patient and caregivers:

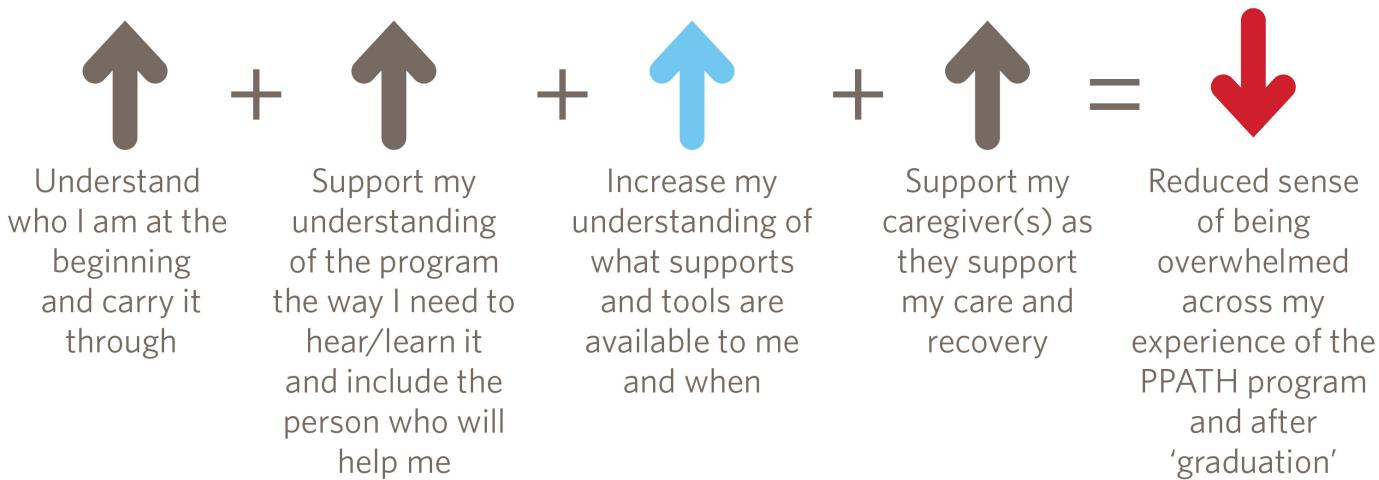
the transition out of the program and the role of the family physician. The 24/7 hotline remains a key resource once at home and therefore should be mentioned throughout the learning program. As well, each component within the learning program should refer to the hotline number and reinforce that the hotline is there for support.

**Learning Program Design Principles**

The following design principles are critical to successful development of components in the learning program. These principles reflect the overarching themes heard throughout the co-design process and serve as a reminder of what is needed to better support the patient and caregiver experience in the PPATH program.

- Provide access as early as possible through multiple channels
- Support different approaches to learning
- Support caregivers and their specific needs
- Ensure consistent information across components
- Use plain language
- Speak to patients and caregivers directly
- Time information appropriately to support understanding
- Build reinforcement of components into the overall patient experience
- Reinforce the relationship of components within the learning program
- Provide components in different languages

With these principles in mind, the following updated diagram illustrates the goal of the learning program in reducing the overall sense of being overwhelmed for patients and caregivers in the PPATH program.



**About Exploratory Prototypes**

Throughout the co-design process, patients, caregivers and staff were invited to describe how the components in the learning program would work. There were also opportunities to create physical expressions of their ideas through a drawing or other creative activity. In some cases, members of the Saint Elizabeth Research Centre expanded on these ideas and created tangible

expressions of what the components might look like and how they might work. These 'exploratory prototypes' were used as catalysts for discussion and to probe the design idea further.

Where an exploratory prototype is available for a component in the learning program, it is noted and/or attached to the relevant design brief.



# Patient Experience Map with About Me pages

## Mapping what to Expect in Hospital, and at Home

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### Why a Patient Experience Map?

Throughout the co-design process, patients and their caregivers said they felt scared and nervous about having cardiac surgery. Many patients spoke about not having a clear understanding of what was to come, particularly in the recovery process, which only intensified their fears and perceived anxiety. Patients suggested a visual representation of the cardiac surgery journey as a way they can see where they are in the journey. The Patient Experience Map provides a clear outline to patients and caregivers what the PPATH program is, how it works from hospital to home, which health care providers are involved, what their roles are, and what resources are available to patients and caregivers. This provides a way for patients and their caregivers to orient themselves within their own experience and better know what supports are available, how to access them and when. The Map includes an About Me section for the patient and caregiver to share information with providers about who they are and what is important to their care.

The Patient Experience Map provides a description of the different roles clinical team members perform, including the cardiac surgeon, Integrated Care Coordinator, Trillium nurses, Saint Elizabeth nurses, occupational therapist, physiotherapist, and social worker. The Patient Experience Map also reinforces all components within the learning program by briefly explaining each component, its purpose, how to access it and plotting reminders about the availability of the components along the experience map.

The map outlines the PPATH experience starting with admission to the hospital and the day of surgery, in-hospital recovery days, discharge from the hospital, first 24 hours at home, first 48-72 hours at home, first 7-10 days at home, transition out of the PPATH program after 30 days at home and the start of the cardiac rehab program beginning 8-12 weeks after the surgery. The map also identifies the informational support in the learning program available to each patient and caregiver throughout the recovery experience, including the PPATH 24/7 hotline.

### Key Elements:

- Highlights key moments in the PPATH program experience including what is going to happen in the hospital and at home
- Describes learning program components and how/when to access them
- Provides opportunity for patients and caregivers to share information, about themselves, with providers
- Can be carried from hospital to home
- Uses visual illustrations to describe the experience moments

### Why an About Me Section?

A core element of the Patient Experience Map is the About Me section. Throughout the co-design process, patients and caregivers wanted a way to share information about themselves, and their life, with members of their cardiac care team. We also know from other research that patients often complain that they have to repeat information about themselves in conversations with different health care providers



and that sharing that information once would be preferred and would contribute positively to their overall experience.

### **About Me Section Focus**

Participants in the World Café completed activities to define what an About Me communication tool should focus on, and why this information is important, as follows:

#### **Family Life**

It is important that patients and caregivers are able to share personal information about their family life which can indicate how they think things through (information and communication based information) and highlight information relevant to scheduling. *Why is this important? This information is about availability of family support.*

#### **Previous Health Conditions**

Patients would like to share information about their health condition, the care received, and how they would be like to be dealt with by health care providers. *Why is this important? Understanding past experiences is important for their current care.*

#### **Context**

It is important to patients that health care providers know about the context of their heart condition. For example, if they led an active, healthy lifestyle and the surgery is the result of genetics, some patients said it would be important to share this information: some patients expressed the experience of stigma and assumptions of a poor lifestyle when receiving cardiac care. *Why is this important? Lifestyle context and expectations can affect patient goals.*

#### **Personality**

Patients and caregivers indicated that it wasn't just important to share the things health care providers should know about them, but also why. It is through the asking of 'why' that the information can be extrapolated into why this information is

also important to the Health Care Provider. *Why is this important? Personality will influence learning & interaction with providers.*

### **Occupation & Hobbies**

Patients and caregivers want to demonstrate their view of the world since this can reveal how they want to engage in their health care. For example, information about their work or hobbies can help providers understand how they might want to receive their care. *Why is this important? View of the world impacts patient goals.*

### **Access to the Patient Experience Map including About Me pages:**

- The Patient Experience Map would be primarily distributed as a printed brochure to patients as soon as they are identified as being in the PPATH program
- The Map and About Me section would remain with the patient and caregiver throughout the PPATH experience, including at home
- Patients and caregivers should be informed at the point of introduction that there is an interactive version on the website and in the mobile application

After receiving the map, patients and caregivers should be encouraged to use the map as a guide to understanding what is planned for recovery and what supports are available in the hospital and at home. For example, the Integrated Care Coordinator or nurse would refer to the experience map during the meeting on Day 2 in hospital to discuss discharge from the hospital, and again on discharge day to illustrate the nursing visit timing, check-in phone calls and to reinforce the 24/7 hotline number.

### **Overall Tone of the Patient Experience Map**

The Patient Experience Map is written in a conversational tone, using plain language and directed toward the patient and their caregiver. Use of icons, and other visual elements, also help to communicate the written content. If production resources allow, the Patient Experience Map should be printed in colour to further support a document that is approachable.

### **How the Patient Experience Map works within the Learning Program**

The Patient Experience Map will act as a guide to the PPATH program as a whole, for patients and caregivers, highlighting each key moment in the cardiac surgery journey through to recovery at home. All of the learning program components and key supports are presented in the Map and can be used as a reminder about what is available to patients and caregivers, including the contact numbers for all important members of the clinical team, the 24/7 hotline number, descriptions of all learning program components and information on how to access them. Like all other learning program components, the Patient Experience Map needs to be reinforced by all members of the clinical care team as a key part of the overall learning program.

### **Resources Needed:**

- Writing and editing expertise
- Content experience (review moments in the experience)
- Branding & graphic design
- Printing
- Coordination with other learning program components
- Training of Trillium staff to direct (and reinforce with) patients and caregivers to the patient experience map
- Training of Saint Elizabeth staff to reinforce the patient experience map (nurses who do any home visits)

### **Exploratory Prototypes**

Based on activities in the co-design series a first prototype of the Patient Experience Map was shared in the World Café event to guide participants between activities. The version included in this package incorporates feedback from the World Café and includes About Me pages for patients and caregivers to use.

# Heart Surgery Education and Recovery Tips Brochure

Re-positioned for Patients and Caregivers

## Why a Re-positioned Brochure?

The HEART brochure that is currently distributed to patients and their caregivers in hospital is seen as a valuable tool for people to learn about the cardiac surgery and the after-surgery experience. Generally, patients and caregivers find the brochure to be thorough in terms of content directed at and most relevant to patients and many find it a comforting tool, knowing so much information is held in one place.

However, throughout the co-design process, caregivers wanted more information directed specifically towards them and the topics that they need to know in their role of caring at home. Understanding that what is required of them is different from what is required of the patient throughout the surgery and recovery process, caregivers expressed the desire to have resources that were tailored to their needs.

By adding a section to the existing HEART brochure for caregivers, there becomes an opportunity to speak directly to their needs and provide the information that is of most interest to them. The caregiver section of the brochure should be easily identifiable with the section heading of “Are you providing support for someone who is having surgery?”

The combination of a HEART and caregiver brochure supports the learning that caregivers require different types of information at different times, than a patient. To reflect this change in the brochure, the new title of *Patient and Caregiver Heart Surgery Education and Recovery Tips*, as proposed by a caregiver in the World Café, is more appropriate.

## Key Features of the *Patient and Caregiver Heart Surgery Education and Recovery Tips Brochure*:

- Rename a brochure as the *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure
- Add a new section for caregivers addressing their specific needs and topics as outlined by caregivers
- Create an online version that is searchable, not just a static PDF
- Have photos that reflect a broader patient group, including younger ages and diversity
- Include photos of equipment needed in the home
- Address topics that are most important for caregivers and most important for patients
- Address the situation of patients who do not have caregivers
- Offer the brochure in different languages
- Reinforce where information in the brochure is available in other formats, such as the Healing Hearts Video Series or Discharge Class

## Access to the *Patient and Caregiver Heart Surgery Education and Recovery Tips Brochure*:

- The *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure should continue to be available in paper to act as a tangible resource that patients and families can keep with them either at home, or take with them to doctor visits, if needed.
- When time permits, the opportunity to have a health care provider walk through the brochure with patients and caregivers would be preferred. This is in addition to the current practice of discussing and sharing the brochure in the Discharge Class.

- The brochure should also be accessible online, hosted on the PPATH Healing Hearts website/mobile app. Ideally, the online version is searchable by topic (so the patient or caregiver can find exactly what information you are looking for quickly) and not just a PDF of the printed brochure. Refer to the Healing Hearts Website & Mobile App brief for further details on functionality of digital platforms.

### Brochure Topics

While there was no consensus on the most-needed topics patients want to know about, people want different things and value different information. Patients and caregivers said there is a need to align the topics in the brochure with the experience map, so the various tools work in tandem as a network of resources. Caregivers spoke about some topics that would be most interesting for them and are to be included in the caregiver section:

#### Caregiver-specific Topics:

- Equipment and home modification (include accurate photos of what equipment looks like)
- What can patients eat  
(What can my family member eat?)
- What pain is normal pain
- Energy levels (what to expect)
- Side effects from medications
- Information on home modifications
- When should I be calling 911  
(what is an emergency situation)
- How to provide encouragement to the patient
- Behavior changes to expect  
(i.e. mood swings, reduced energy, etc.)
- Where to get the required equipment ahead of time
- Add actual pictures of the equipment required for at home
- Add a section discussing what to do if a patient doesn't have a caregiver in the home

### When to Introduce the Brochure:

Introduction of the *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure should be as early as possible in the cardiac experience. Ideally, the patients and caregivers would be given the brochure when they first learn the patient will be having cardiac surgery, before being admitted into hospital. When possible, a health care provider would walk through the brochure with both the patient and caregiver and direct them to the online version by providing the website address and directions to download the mobile app (when available). When patients are admitted to the hospital, their caregivers should be reminded about what information is available in the brochure and what sections might be most relevant to them and their caregiver. By the time they speak with the Integrated Care Coordinator or the nurse at intake, they should have received the brochure and the information to access online resources.

If patients and caregivers have not yet received the brochure, it is distributed in the discharge class as is the current practice. Topics in the brochure are reinforced through discussion in the discharge class.

If the surgery is unplanned, the brochure should be introduced to the caregiver (and patient if possible), as early as possible. When it is introduced, there should be an acknowledgement that urgent cardiac surgery can be a traumatic experience, especially for family members, and there is a lot of information given to the patient and families in a short period of time which can be overwhelming. The brochure should be introduced as early as possible, it must be clear what information can be found where, as well as how to access the online version. It should also be reinforced that the brochure links to other sources to access the information, such as the video series and the discharge class, if the patient or caregiver would prefer to learn in a different way that better suits them.

After surgery, when the patient is in recovery, they are to be reminded that the brochure is available.

### **Overall Tone of the *Patient and Caregiver Heart Surgery Education and Recovery Tips Brochure***

Patients and caregivers spoke about wanting the brochure to be written in a conversational tone, using plain language and avoiding any clinical jargon. They want the brochure to be easily navigated and suggested a searchable online version. Patients want pictures included in the brochure to be more realistic to what they will experience. This includes real pictures of equipment they will be using and photos that represent a broader range of patients in the brochure, specifically not just showing older people as having cardiac surgery. Many patients thought that the people represented in the brochure did not reflect them and therefore would not be aligned with their experience.

Caregivers want the caregiver section to speak directly to them and their perspective as the person providing support. It is important that this section of the brochure addresses caregiver-specific needs, including tips for their own self-care, and well-being.

The language and overall tone of the brochure should be broad enough that it speaks to people who have a caregiver but can also be understood as support for those patients who do not have a caregiver in the home to support their recovery.

### **How the Brochure Works within the Learning Program**

Topics that are covered in the *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure should be highlighted in other components of the learning program, such as the discharge class, Healing Hearts Video Series and through the Healing Hearts Volunteers.

For example, when a topic in the brochure is also in a Healing Hearts Video, it should be noted in the brochure that there is a corresponding video and where to access that video. Additionally, when topics in the brochure are covered in the discharge class, patients and caregivers should be informed of where the topic can be found in the brochure.

### **Resources Needed**

- Writing & editing expertise
- Printing
- Photographer (for updated pictures in the brochure)
- Equipment to be photographed
- Graphic designer
- Identification of patients & caregivers (invitations to participate & consent)
- Appropriate staff from Trillium and Saint Elizabeth for content development of the caregiver section
- Web/IT for posting online
- Coordination with other learning program components
- Training of Trillium staff to direct (and reinforce with) patients and caregivers to the brochure
- Training of Saint Elizabeth staff to reinforce the brochure (nurses who do any home visits)

# The Healing Hearts Video Series

## Sharing Information through Different Perspectives

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### **Why a Healing Hearts Video Series?**

Throughout the co-design process, patients and caregivers said they wanted the ability to access information when it is of most interest to them. Some patients and caregivers learn best through audiovisual communication, and many supported the idea of a video series with information. In addition, caregivers thought it would be useful to have a series of videos that were focused on their information needs.

As patients and caregivers spoke about the overwhelming amount of information provided by health care staff and through the printed materials they already receive, they said that the video series would break up this information into more focused topics. As with the other elements in the PPATH Healing Hearts Learning program, the video series should be organized so that there are different videos for focused topics that would be easily located and viewed when necessary, according to the needs of the patient and caregiver. The topics selected for the video series were determined by patients, caregivers, and health care staff throughout the co-design process and are listed below. The listed topics respond to what patients and caregivers said was most important to know and share with others. Individual videos should be created according to each topic and be no more than 2 minutes in length. It is important to patients and caregivers to have doctors, nurses and therapists deliver clinical information because of their clinical expertise. But hearing about personal experience from someone who has been through this before is of equal, and sometimes greater, importance to patients and caregivers.

The video series would offer the opportunity to hear from patients and caregivers who have been through the cardiac surgery experience. This perspective was seen as extremely valuable and is currently only heard through an in-person connection with a Healing Hearts Volunteer during the Discharge Class that currently takes place in the hospital.

### **Key Features of the Healing Hearts Video Series:**

- Address topics as outlined by patients and caregivers as most important
- Have separate patient/caregiver-led and health care provider-led videos for each topic
- Patient-/caregiver-led videos conversational and approachable, using real-life experiences and plain language
- Have short videos, less than 2 minutes
- Patient and caregiver-led videos are filmed in a non-clinical environment

### **Access to the Video Series:**

- Make videos accessible both in the hospital and at home.
- In the hospital, have a dedicated Healing Hearts Cardiac TV channel or access to a tablet upon request so patients, caregivers and family can watch the videos while they are resting or waiting.
- Make the video series accessible at home through a website and/or an app available on smart devices.

### **Video Series Topics Focused on the Patient — 2 Videos per Topic:**

- Stairs, exercise dos and don'ts, walking program (split into 2 videos)
- Sleeping
- Showering
- Bowel Movement
- Medication (& pain management)
- Getting in and out of bed (bed mobility)
- Getting in and out of the car
- Energy levels (what to expect)
- Deep breathing/coughing exercises
- About the incision/sternum healing
- Lifting
- The first day home from the hospital

### **Video Series Topics Focused on the Information Caregivers Want to Know — 2 Videos per Topic:**

- Taking time off work
- What tasks should I expect to do?
- What are my responsibilities?
- What is “normal”
- What can I do to make my family member more comfortable?
- Where can I go if I need help?
- Caregiver exhaustion and stress
- Incision care and how to spot infection
- Assisting with movements
- Food – what is safe to feed my family member?
- Heart health safety
- How can I prepare my home before the surgery?
- Helping my family member shower
- Medication & pain management
- Helping get my family member in and out of the car

### **When to Introduce the Video Series**

Introduction of the video series should be as early as possible when a patient knows he or she is going to have surgery. The patients and caregivers would learn about the series from their doctor/surgeon, nurse, and Integrated Care Coordinator if they have interaction with the Trillium cardiac team in advance of their surgery and before being admitted into hospital.

When patients are admitted to hospital, they would be reminded that the video series is available if they would like to view it.

In circumstances when the surgery is unplanned, the video series should be introduced to the caregiver and patient, as early as possible. Understanding that unplanned cardiac surgery can be a traumatic experience, including for family members, there is a lot of information given to the patient and families in a short amount of time which can be overwhelming. Therefore, the videos should be introduced to the caregiver as soon as a patient is admitted into hospital. Patients and caregivers should be told how and when they can access the videos at a time that is appropriate for them.

The nature of the videos — patient-led, caregiver-led, and clinician-led discussions — should be mentioned to patients and caregivers. After surgery and when the patients are still in the hospital, they should be reminded by the nurses each day that the video series is available online if they would like to view it.

### **Overall Tone of the Video Series**

Patients and caregivers described the videos as needing to have a “relaxed” and “friendly” tone with a real feel. We understood this to mean the people in the video must seem approachable and the information described in each video needs to be given in a conversational way, using plain language and real-life examples that clearly relate to a patient or caregiver’s everyday life and what they will experience. For example, when an Occupational Therapist describes motions that should be avoided, such as “reaching, twisting, bending”, it may be preferable to describe those motions in the context of everyday activities. For example, the motions could be described in the context of grocery shopping: ‘don’t reach up for something on a top shelf, and instead only grab something on an eye-level shelf. Patients and caregivers thought that an informal, casual and composed approach would help with reducing stress about the amount of information they needed to retain.



Pairing the patient/caregiver videos with a corresponding health care provider/clinician video is also important as patients and caregivers do want to hear the 'expert' perspective. It is important that these videos also have a friendly and accessible tone and use plain language without clinical jargon so that it can be understood by anyone.

### **How the Videos will Work within the Learning Program**

Topics that are covered in the video series should be referred to in other elements of the learning program, such as the discharge class, *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure and through the Healing Hearts Volunteers.

For example, the *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure would note each topic in the brochure that has a video, and in the discharge class, patients and caregivers should be told in person that each topic covered has a corresponding video.

Similarly, at the end of each video there should be a reference to other learning sources that support that topic. For example, at the end of the video on sleeping, there should be a note to let viewers know that more information is available in a specific section of the *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure and that this topic is also discussed in the discharge class which takes place two days a week on the Cardiac Unit.

### **Resources Needed to Produce the Video Series:**

- Video crew & editing expertise
- Graphics for branding the Healing Hearts Video Series and to intro and exit each video

- Staff time for shoot
- Identification of patients & caregivers (invitations to participate & consent)
- Time and compensation or recognition for patients & caregivers to appear in the videos
- Content development for health care providers videos
- Content outline for patient and caregiver videos
- Web/IT for posting online (or on a dedicated website hosting an initial pilot is to establish a YouTube channel)
- Coordination with other learning tools (e.g. *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure, discharge class, etc.)
- Training of Trillium staff to direct (and reinforce with) patients and caregivers to the videos
- Training of Saint Elizabeth staff to reinforce the videos (nurses who do any home visits)
- Information about the video series should be included in the red discharge folder

### **Exploratory Prototypes**

As part of the co-design process, video prototypes were created and shared at the World Café event and are available to guide the preparation of the final videos. These prototypes are an important tool and should be used as a guide, together with this design brief, in the creation of the Healing Hearts Video Series.

### **Future Considerations**

In the context of discussions of desirable supports to caregivers, it was suggested that helpful videos could be embedded within interactive learning modules to increase their impact. This is an idea that might be explored as a next step after the learning program is fully in place.

# Discharge Class: Preparing to Go Home

## Expanding Access

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### Why a Discharge Class?

Throughout the co-design process we heard about the current Discharge Class, held two times a week during the day on the cardiac unit, for patients and caregivers to prepare to go home and learn important information to support recovery. Patients and caregivers who had attended a discharge class said they liked the chance to learn in-person as it gave them an opportunity to talk about a full spectrum of scenarios and ask questions.

Patients and caregivers were also positive about including a Healing Hearts Volunteer as a co-lead, with the occupational therapist and social worker, as they felt they could relate to hearing the real life experience of someone who had been through a cardiac surgery experience and recovered. Although the clinical information offered in the class is seen as important, hearing about personal experiences from a peer was considered to be equally, if not of greater importance.

Patients and family members who attended the class acknowledge that information given during the class is too fast and not easily retained. This is particularly true for caregivers who will take on the responsibility of care once at home.

An alternate approach would include an open forum for people to talk about a full spectrum of scenarios in the context of their own experiences. Patients and caregivers value the interactive nature of an open forum discharge class, focused more on their needs and questions they identify as being of importance in addition to the content laid out by the clinicians.

Many patients and caregivers said they were either unable to attend the class due to the limited times it was offered, or they had not heard about the class at all. Caregiver and patients said the class should be offered more frequently throughout the week and at different times, and in the evenings. Additionally, many patients, caregivers and health care staff agreed an online version of the class would be beneficial. The online version might simply be a recording of an in person discharge class that is posted online for patients and caregivers to access at a time that best suits them. The overall consensus was that the primary benefit of the discharge class was the opportunity for interaction with other patients and families and the ability to ask questions. An online recording would not support this need, however it would support patients and caregivers who would not be able to attend in-person. In addition, an online version would provide an opportunity for reinforcement, allowing people that did attend a class to go back and review the information again, at their own pace

The class would also act as an opportunity to connect patients and caregivers to other resources that exist within the learning program, such as the *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure, the Healing Hearts Video Series and the website/mobile app. The occupational therapist, social worker and Healing Hearts Volunteer are to introduce the discharge class attendees to each of these resources and let them know where they can be accessed. Further, when topics covered in the discharge class are available in the other resources, it should be made clear where to locate that information.

For example, when the occupational therapist is providing information about exercise do's and don'ts, they should inform people in the discharge class that there are videos available on this topic as well and how to view them.

### Key Features:

- Provide more class time options on different days and times of the day, including evenings
- Balance 'lecture-style' learning with more time for questions and discussion
- Provide real life examples and scenarios shared by the Healing Hearts Volunteer
- Increase awareness about the class and when it is being held
- Create a video recording of the discharge class for viewing online
- Inform patients and caregivers before surgery, when possible, of the days and times the discharge class will be held
- Inform patients and caregivers before surgery, when possible, that there is an online video of the discharge class
- Direct patients and caregivers to other components where more information on the topics shared in class is available within the learning program
- Focus the discharge class topics to reflect those identified by patients and caregivers

### Access to the Discharge Class:

- Although health care providers said it was important for the discharge class to happen after surgery has already taken place, patients and caregivers did not all agree
- There should be more class time options, including different times of the day and more days of the week
- The class needs to be advertised as many patients and caregivers spoke about how they did not know a discharge class existed
- The primary method for delivery of the discharge class is to continue to be an in-person format

- An online version of the class would be available for those who could not attend an in-person class or would like to review the material of the class. The online version would be a discharge class that was recorded and posted as a video online.

### Discharge Class Topics

During the World Café, patients and caregivers identified the topics they felt were the most important to learn, and discuss, in the discharge class.

- Day-to-day activities after surgery and limitations
- What can the caregiver expect/what can they do
- What can patients expect
- Wound care
- Who can visit me at the hospital
- What do I do if I am alone
- Pain/emotions
- Medication
- Pressure injuries
- Preparing the home
- Weighing
- Water retention prevention
- Showering
- Exercises to do
- What will change
- What nursing care is available
- Average length of stay

### When to Hold the Discharge Class

Many patients and caregivers spoke about how they would like the choice to attend the discharge class BEFORE the surgery and, if possible, before hospital admission. Offering the class as an information gathering option earlier would allow patients and caregivers to decide what works best for them and their needs. The discharge class should be introduced early in the cardiac experience, and as close to when the patient is first identified as needing cardiac surgery. Within the PPATH program, the Integrated Care Coordinator or nurse, who meet with patients after intake and before surgery, should let patients and caregivers know about the discharge class and

when and where it takes place. They should also let patients and caregivers know that the discharge class is part of a learning program and refer to the patient experience map which includes a short description of the class.

When surgery is unplanned, the class should be introduced to the caregiver (and patient if possible), as early as possible upon arrival at Trillium Hospital. Because an unplanned cardiac surgery can be a traumatic experience, including for family members, there is a lot of information given to the patient and families in a short period of time. This barrage of information can be overwhelming and add to an already stressful situation. Information given about the discharge class may not be retained by family members in such cases and should be reinforced by clinical staff on the cardiac unit. As well, when the class is introduced, it should be made clear what information discharge class addresses, that there is an opportunity to speak to a Healing Hearts Volunteer who has had cardiac surgery in the class and that they will be able to ask any questions they might have.

When the discharge class is introduced, and reinforced, it must also be made clear that there is an online version and how patients and caregivers can access it.

After surgery and when the patient is in recovery, they should be reminded about the weekly schedule of the class and that the online version is available if they would like to view it.

### **Overall Tone of the Discharge Class**

A friendly and informal tone is important to patients and caregivers who attend the discharge class. They would prefer an open forum structure as opposed to the lecture-style structure of the current class, as this would help create a more relaxed and supportive environment. Patients and caregivers want the opportunity to ask questions and hear the experiences of others who have gone through the

surgery or are going to have the surgery. Information presented in the class should be done so in a way that avoids clinical jargon and incorporates or builds on examples in patients' and caregivers' likely day-to-day lives once home.

### **How the Discharge Class Works within the Learning Program**

Reinforcing the discharge class content is important and the topics that are covered in the class should be highlighted in other elements of the learning program, such as the *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure, Healing Hearts Video Series and through the Healing Hearts Volunteers.

For example, when introducing a topic in the discharge class, the facilitator should also identify where additional information on that same topic can be found in the brochure and how to access a corresponding video from the video series.

### **Resources Needed:**

- Appropriate staff to lead discharge class 3 x per week (rotating times of the day)
- Healing Hearts Volunteers
- Content development where new content is needed
- Video crew to record class/ provide online version
- Web/IT for posting online
- Branding & graphics, if needed, for online video
- Identification of patients & caregivers (invitations to participate & consent) to participate in the discharge class to be videotaped
- Coordination with other learning tools (e.g. *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure, Healing Hearts Video Series, Website/Mobile App, etc.)
- Training of Trillium staff to direct (and reinforce with) patients and caregivers to the discharge class
- Training of Saint Elizabeth staff to reinforce that an online discharge class is available (nurses who do any home visits)

# Healing Hearts Website and Mobile App

## Accessing Online Information Easily

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### **Why a Website and/or Mobile App to Support PPATH?**

In early stages of the co-design process, patients and caregivers were generally lukewarm to the idea of accessing information through a website or mobile application. However, many acknowledged that digital applications were the way of the future. With this in mind, there were activities to further explore the desirability of a website or mobile app at the World Café. If digital tools were not part of people's daily lives, they were not interested in using them to support their learning and therefore did not participate in the activity. However, for those that did give feedback on the website and mobile app, there was agreement that a responsive website and/or a mobile application would be beneficial and desirable.

A website that is searchable, with links to other resources, was seen as a good way to accessing all the information in the learning program both before and after surgery. Patients and caregivers agreed that the website should link to the video series, the *Patient and Caregiver Heart Surgery Education and Recovery Tips* brochure, a Q&A section and pre-op information. Creating a way to contact a health care provider was also desired.

In addition to a website, a mobile app that reflects the ideas for the website would be welcome, plus elements unique to this platform. Participants noted that an app should be accessible at any time and might be personalized to their own conditions, needs and wants. The app should be responsive, anticipate needs and have the ability to record goals. The app

was imagined, in part, as a coaching tool that would be best used to give patients the information they want, when they want it, so they are better prepared to make changes on their own.

### **Key Features of the Website and Mobile App:**

- Make content consistent with content from the *Patient and Caregiver Heart Surgery Education & Recovery Tips* brochure
- Have a visually prominent link to the Healing Hearts Video Series
- Include an interactive version of the Patient Experience Map
- Include all necessary contact information, including the 24/7 hotline, Integrated Care Coordinator and Cardiac Surgeon's office
- Integrate exercise and walking programs
- Provide feedback to patients on exercise and walking program progress (primarily in the mobile app)
- Include a Q&A section and place to ask questions
- Integrate pre-op information
- Include information about rehab programs and relevant area supports (e.g. pharmacies that are close by)
- Have clear navigation that is easy to use

### **Access to the Website and Mobile App:**

- Early access is especially important for these tools so patients and caregivers are able to explore the platform in advance of the stress of the surgery and recovery itself. Ideally, the website and mobile app should be introduced as part of the first visit to the surgeon's office.

### **Desired Content and Topics for the Website and Mobile App:**

- All content from the printed brochure
- Links to the Healing Hearts Video series
- Patient Experience Map & content (with the ability to move around the map)
- Contact information (hotline, Integrated Care Coordinator, Cardiac Surgeon's Office, etc)
- Walking program (currently distributed by the physiotherapist in paper form)
- Relevant area supports (e.g. pharmacies that are close by)
- Information about rehab programs
- Q&As and a place to ask questions
- Pre-op information

### **When to Introduce the Website and Mobile App**

As with the other components of the learning program, introduction of the website and mobile app should be as early as possible in the cardiac experience. Ideally, the patients and caregivers would learn about the series through their doctor/surgeon and nurse and Integrated Care Coordinator if they have interaction with the Trillium cardiac team in advance of their surgery. When patients are admitted to hospital, they should be told by the nurse and Integrated Care Coordinator that there is a PPATH website and that an app can be downloaded if they have a smart phone or tablet. Patients and caregivers should also find a link to the website, and where to download the app, in the PPATH Patient Experience Map.

If the surgery is unplanned, the website and mobile application should be introduced to the caregiver and patient as early as possible. Since unplanned cardiac surgery can be a traumatic experience, especially for family members, there is a lot of information given to the patient and families in a short amount of time which can be overwhelming. For those that already integrate digital tools into other areas of their lives, a website and mobile application may be

a welcome access point. However, for those patients and caregivers who are not interested or do not have access to the internet or a mobile device, the doctor/surgeon, nurse and Integrated Care Coordinator should tell patients, when introducing the learning program, that they are able to access the same information available on the website and mobile app, through other tools such as the printed brochure, the Experience Map and the discharge class.

### **Overall Experience of the Website and Mobile App**

Patients and caregivers consistently commented that both a website and mobile app must be easy to use and that their experience to find information must not require going through multiple screens. Users should have the ability to select information based on the pre- or post-surgery experience at the onset and information should be concise and easy to read.

### **How the Website and Mobile App work within the Learning Program**

The website and mobile application would support the other elements of the learning program, and would reinforce learning across the cardiac surgery experience. As these digital platforms would be the primary method for sharing the Healing Hearts Video Series, this link needs to be clearly highlighted within the navigation.

### **Resources Needed to Build the Website and Mobile App:**

- Content from other elements in the learning program
- Website and mobile application expertise/partner
- Graphics for visual direction and branding
- Staff time for addition content where needed
- Training of Trillium staff to direct (and reinforce with) patients and caregivers to the website and mobile app
- Training of Saint Elizabeth staff to reinforce the website and mobile app (nurses who do any home visits)



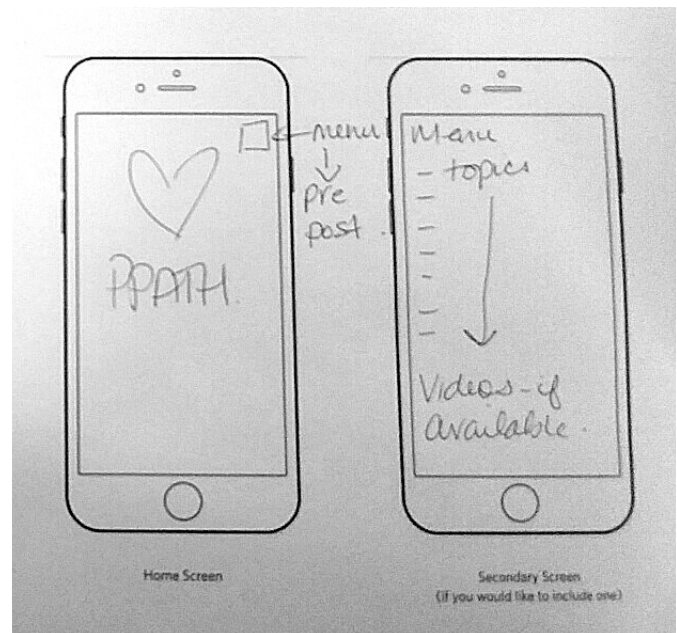
- Information about the website and mobile app is to be included in the Patient Experience Map booklet on page 1 (see the exploratory prototype provided as part of the design brief package) which is to be added to the red discharge folder.

### The Red Discharge Folder

Although the red discharge folder has not been re-designed as part of the learning program, the PPATH Patient Experience Map, with website link and mobile app information, should be added to the folder.

### Exploratory Prototypes

The adjacent sketch is from a World Café participant illustrating the home screen and secondary screen navigation for a mobile application.

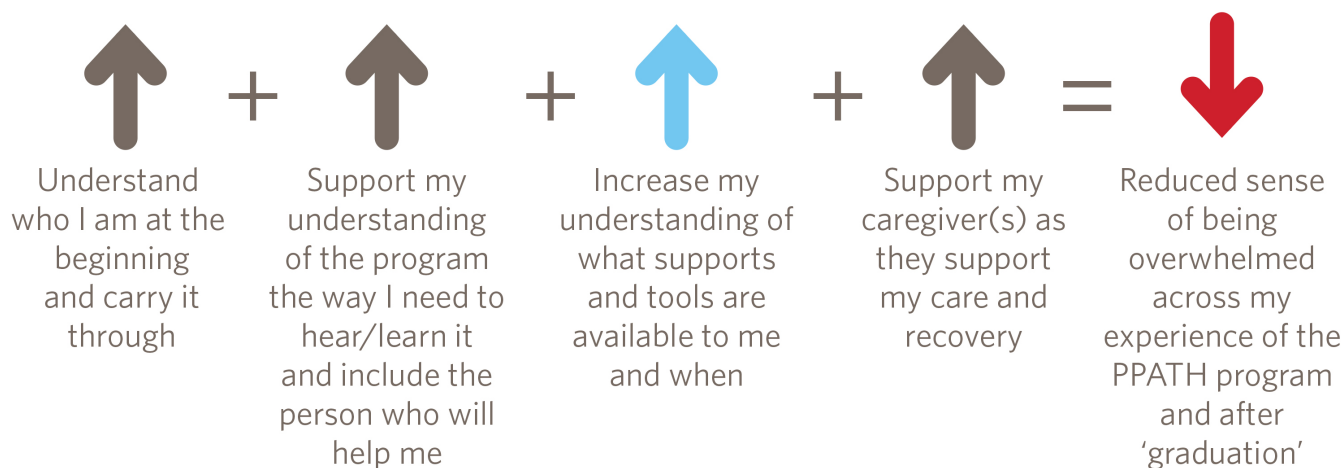




# Measuring the Implementation and Impact of the PPATH Healing Hearts Learning Program

The co-design process was undertaken to improve the transition experiences of patients and caregivers in the PPATH program. The results of the co-design process — the plan for the PPATH Healing Hearts Learning Program — and the expected outcomes have been developed and endorsed by all participants and stakeholders. A simplified logic model for the changes

is illustrated below, with the arrows pointing upward together representing the aims and expected effects of the learning program (e.g., increased understanding, increased support), with the impact represented by the downward arrow, a reduced sense among patients and caregivers of being overwhelmed.



Moving from the plan to implementation and actually achieving the expected outcomes are the next important steps. As we know from experience and the literature, having a great set of ideas and the intent to put them into action is an excellent starting place, but there are many factors, including how

well the ideas are implemented and brought to life that can influence the achievement of the outcomes. Hasson,<sup>1</sup> adapted a framework developed by Carroll et al.,<sup>2</sup> for understanding the factors that can affect the fidelity of the implementation. Hasson's framework is reproduced in Figure 1.

<sup>1</sup> Hasson H. Systematic evaluation of implementation fidelity of complex interventions in health and social care. *Implementation Science*. 2010 Sep 3;5(1):67.

<sup>2</sup> Carroll C, Patterson M, Wood S, Booth A, Rick J, Balain S. A conceptual framework for implementation fidelity. *Implementation Science*. 2007 Nov 30;2(1):40.

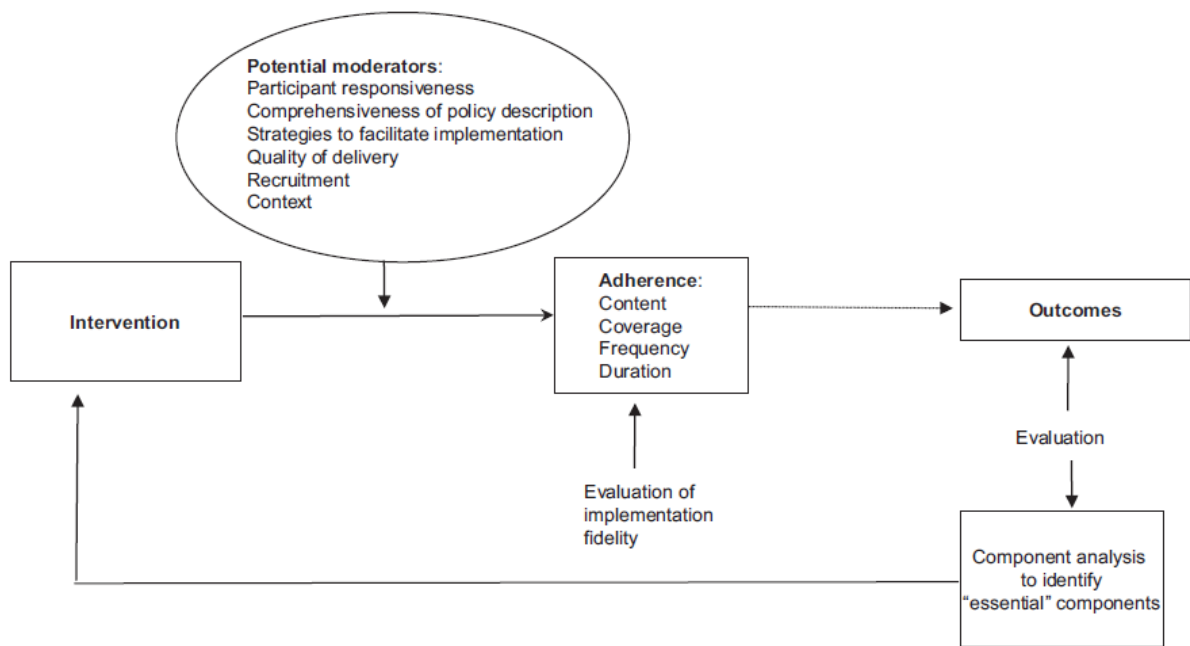


Figure 1: The modified conceptual framework for implementation fidelity (originally from Carroll et al).

Table 1 provides a description of the factors within the categories of Adherence and Potential Moderators as they relate to the implementation of the PPATH Healing Hearts Learning Program.

FACTORS	DESCRIPTION	EVALUATION CYCLE
Content	Were the elements of the Learning Program implemented as outlined in the design briefs?	All phases
Coverage	Were all patients in the PPATH program and their caregivers offered the Learning Program?	All phases
Frequency	Were the elements of the Learning Program introduced to, and reinforced for, patients and caregivers by Trillium Health Partners and Saint Elizabeth providers as intended?	All phases
Duration	Was the Learning Program offered to patients in the PPATH program and caregivers from their first encounter with Trillium Health Partners providers until their last encounter with Saint Elizabeth providers?	All phases

Table 1 continues on the following page.

**Table 1, cont.**

FACTORS	DESCRIPTION	EVALUATION CYCLE
<b>POTENTIAL MODERATORS</b>		
<b>Participant responsiveness</b>	Were providers, patients and caregivers engaged with the elements of the Learning Program? Did they find the elements of the Learning Program aligned with their goals? Were the providers, patients and caregivers satisfied with the Learning Program?	All phases
<b>Intervention complexity</b>	How complex was the Learning Program to implement?	*
<b>Comprehensiveness of policy description</b>	Did the design briefs describe the Learning Program in sufficient detail to facilitate implementation?	All phases
<b>Strategies to facilitate implementation</b>	Did Trillium Health Partners and Saint Elizabeth providers find the strategies for implementing the elements of the Learning Program effective?	*
<b>Quality of delivery</b>	When Trillium Health Partners and Saint Elizabeth providers introduced the Learning Program and reinforced its availability, was it done in a way that encouraged uptake by patients and caregivers?	All phases
<b>Recruitment</b>	Were all patients in the PPATH program and their caregivers offered the Learning Program? (same as Coverage, above)	All phases
<b>Context</b>	What financial, operational and organizational factors influenced the implementation of the Learning Program?	*

\* To be determined in the implementation planning

This framework will guide the evaluation of the implementation. Because the Learning Program has components at various stages of readiness for implementation, it is likely that the components will be implemented in phases. The evaluation plan therefore has been developed to respond to the decisions that will be made about component timing and availability.

As outlined in Table 1, the factors relating to Adherence (content, coverage, frequency and duration) will be measured in each phase of implementation, as well as some of the Potential Moderators that relate specifically to the design briefs (participant responsiveness, comprehensiveness of policy description, quality of delivery, and recruitment). The evaluation approach for the other elements (intervention complexity, strategies to facilitate implementation and context), will be developed by the Trillium Health Partners/Saint Elizabeth partnership as part of the implementation planning. In

addition, there will be reliance on the HSPRN evaluation of outcomes, including patients' and caregivers' assessment of their experience of the transition.

The evaluation of the implementation of the Learning Program will proceed by way of surveys asking questions about Adherence factors and the subset of Potential Moderators related to the design briefs, with the questions being posed in a way that reflects the elements in the simplified logic model for the Learning Program (above). Table 2 provides a list of the essential elements of the overall program and of each component, and sample draft questions that would be posed to patients and caregivers in surveys. Table 3 provides sample draft questions for health care providers involved in delivering the PPATH program. The questions are presented in draft, since the content, phrasing and ordering of the questions will need to be adapted to reflect the phases in the implementation.

**Table 2: Draft survey questions for all implementation phases for patients and caregivers regarding content, coverage, duration, frequency, participant responsiveness, comprehensiveness of policy description, quality of delivery, and recruitment.**

KEY ELEMENTS OF THE LEARNING PROGRAM	SAMPLE QUESTIONS IN SURVEYS (patients and caregivers)
<i>Elements in every component</i>	<i>To be asked in all phases</i>
<ul style="list-style-type: none"> <li>Provide access as early as possible through multiple channels</li> <li>Support different approaches to learning</li> <li>Support caregivers and their specific needs</li> <li>Ensure consistent information across components</li> <li>Use plain language</li> <li>Speak to patients and caregivers directly</li> <li>Time information appropriately to support understanding</li> <li>Build reinforcement of components into the overall patient experience</li> <li>Reinforce the relationship of components within the learning program</li> <li>Provide components in different languages</li> </ul>	<ul style="list-style-type: none"> <li>How are you coping?</li> <li>At any time during your cardiac surgery journey, did you feel overwhelmed? When?</li> <li>Have you heard of the Healing Hearts Learning Program?</li> <li>What health care providers mentioned the Learning Program to you?</li> <li>When did you first hear about the Learning Program?</li> <li>What part of the Learning Program have you used?</li> <li>Did you find that information in one place was also available in another part of the Learning Program?</li> <li>Did you find the language easy to understand?</li> <li>Did you find the information easy to understand?</li> <li>Did the Learning Program give you the information you needed when you needed it?</li> </ul>
<b>Patient Experience Map with About Me Pages</b>	
<ul style="list-style-type: none"> <li>Highlights key moments in the PPATH program experience including what is going to happen in the hospital and at home</li> <li>Describes learning program components and how/when to access them</li> <li>Provides opportunity for patients and caregivers to share information, about themselves, with providers</li> <li>Can be carried from hospital to home</li> <li>Uses visual illustrations to describe the experience moments</li> </ul>	<ul style="list-style-type: none"> <li>Did you receive a Patient Experience Map?</li> <li>Did you understand the Patient Experience Map?</li> <li>Did you find the Patient Experience Map useful?</li> <li>Did the Patient Experience Map help you find know what was going to happen in the hospital and at home?</li> <li>Did the Patient Experience Map guide you other parts of the Learning Program?</li> <li>Was the Patient Experience Map easy to keep with you in the hospital and at home?</li> <li>Did you use the About Me section in the Patient Experience Map?</li> <li>Would you have preferred to have the Patient Experience Map in a language other than English?</li> </ul>

Table 2 continues on the following page.

Table 2, Cont.

KEY ELEMENTS OF THE LEARNING PROGRAM	SAMPLE QUESTIONS IN SURVEYS (patients and caregivers)
<b><i>Patient and Caregiver Heart Surgery Education and Recovery Tips Brochure</i></b>	
<ul style="list-style-type: none"> <li>▪ Brochure renamed to <i>Patient and Caregiver Heart Surgery Education and Recovery Tips</i> brochure</li> <li>▪ New section added for caregivers addressing their specific needs and topics as outlined by caregivers</li> <li>▪ Creation of online version that is searchable; not just a static PDF</li> <li>▪ Photography reflects a broader patient group, including younger ages and diversity</li> <li>▪ Include photos of equipment needed in the home</li> <li>▪ Address topics outlined as most important for caregivers and most important for patients</li> <li>▪ Address the situation of patients who do not have caregivers</li> <li>▪ Reinforce where information in the brochure is available in other formats, such as the Healing Hearts Video Series or Discharge Class</li> </ul>	<ul style="list-style-type: none"> <li>▪ Did you receive a <i>Patient and Caregiver Heart Surgery Education and Recovery Tips</i> brochure?</li> <li>▪ Did it seem that it was prepared with you in mind?</li> <li>▪ If you are a caregiver, was the Caregiver section useful?</li> <li>▪ If you needed some equipment in your home, did the pictures in the brochure help you know what to expect?</li> <li>▪ What topics in the brochure did you find useful to you?</li> <li>▪ Were there topics that weren't in the brochure that should have been?</li> <li>▪ If the topics weren't in the brochure, could you find them in other parts of the Learning Program?</li> </ul>
<b>The Healing Hearts Video Series</b>	
<ul style="list-style-type: none"> <li>▪ Accessible in both hospital and at home</li> <li>▪ Address topics as outlined by patients and caregivers as most important</li> <li>▪ There are separate patient/caregiver-led and health care provider-led videos for each topic</li> <li>▪ Patient/caregiver-led videos are conversational and approachable, using real-life experiences and plain language</li> <li>▪ Videos are short; less than 2 minutes</li> <li>▪ Patient and caregiver-led videos are filmed in a non-clinical environment</li> <li>▪ Videos are available on a dedicated TV channel in the hospital</li> <li>▪ Videos are available through a website and/or mobile application</li> </ul>	<ul style="list-style-type: none"> <li>▪ Did you hear about the Healing Hearts Video Series?</li> <li>▪ Have you seen any of the videos in the series?</li> <li>▪ Where did you see the videos?</li> <li>▪ What videos did you find useful to you?</li> <li>▪ Were there topics that you would like to have been able to see a video on?</li> <li>▪ Did it seem that the videos were prepared with you in mind?</li> <li>▪ Were the videos too short, just right, too long?</li> <li>▪ Were the videos featuring patients relevant to you?</li> <li>▪ Were the videos featuring caregivers relevant to you?</li> <li>▪ Were the videos featuring health care providers relevant to you?</li> </ul>

Table 2 continues on the following page.

**Table 2, Cont.**

KEY ELEMENTS OF THE LEARNING PROGRAM	SAMPLE QUESTIONS IN SURVEYS (patients and caregivers)
<b>Discharge Class</b>	
<ul style="list-style-type: none"> <li>• Provide more class time options on different days and times of the day, including evenings</li> <li>• Balance 'lecture-style' learning with more time for questions and discussion</li> <li>• Provide real life examples and scenarios shared by the Healing Hearts Volunteer</li> <li>• Increase awareness about the class and when it is being held</li> <li>• Create a video recording of the discharge class for viewing online</li> <li>• Inform patients and caregivers before surgery, when possible, of the days and times the discharge class will be held</li> <li>• Inform patients and caregivers before surgery, when possible, that there is an online video of the discharge class</li> <li>• Direct patients and caregivers to other components where more information on the topics shared in class is available within the learning program</li> <li>• Focus the discharge class topics to reflect those identified by patients and caregivers</li> </ul>	<ul style="list-style-type: none"> <li>• Did you hear about the Discharge Class?</li> <li>• If so, how did you hear?</li> <li>• When?</li> <li>• Were you able to attend a Discharge Class?</li> <li>• If not, why not?</li> <li>• If you were unable to attend, did you know there is a version of the Discharge Class online?</li> <li>• If so, have you seen the online version of the Discharge Class?</li> <li>• What parts of the Class did you find useful to you?</li> <li>• Are there topics that you would like to have been able to hear about in the Class?</li> <li>• Did it seem that the Class videos were prepared with you in mind?</li> <li>• Did you find that there was enough chance for you to ask questions and discuss your concerns?</li> <li>• In the Discharge Class, were you given information about other parts of the Learning Program?</li> </ul>
<b>Healing Hearts Website and Mobile App</b>	
<ul style="list-style-type: none"> <li>• Content is consistent with content the <i>Patient and Caregiver Heart Surgery Education &amp; Recovery Tips</i> brochure</li> <li>• Visually prominent link to the Healing Hearts Video Series</li> <li>• Include an interactive version of the Patient Experience Map</li> <li>• Include all necessary contact information, including the 24/7 hotline, Integrated Care Coordinator and Cardiac Surgeon's office</li> <li>• Integrate exercise and walking programs</li> <li>• Provide feedback to patients on exercise and walking program progress</li> <li>• Include a Q&amp;A section and place to ask questions</li> <li>• Integrates pre-op information</li> <li>• Include information about rehab programs and relevant area supports (e.g. pharmacies that are close by)</li> <li>• Have clear navigation that is easy to use</li> </ul>	<ul style="list-style-type: none"> <li>• Did you hear about the Healing Hearts website/mobile app?</li> <li>• If so, how did you hear?</li> <li>• When?</li> <li>• Have you used the Healing Hearts website/mobile app?</li> <li>• If not, why not?</li> <li>• Did you find the Healing Hearts website/mobile app easy to use?</li> <li>• What parts of the Healing Hearts website/mobile app did you find useful to you?</li> <li>• Are there topics that you would like to have been able to see on the Healing Hearts website/mobile app?</li> <li>• Did it seem that the Healing Hearts website/mobile app was prepared with you in mind?</li> </ul>

**Table 3: Draft survey questions for all implementation phases for Trillium Health and Saint Elizabeth health care providers regarding content, coverage, duration, frequency, participant responsiveness, comprehensiveness of policy description, quality of delivery, and recruitment.**

KEY ELEMENTS OF THE LEARNING PROGRAM	SAMPLE QUESTIONS IN SURVEYS (health care providers)
<i>Elements in every component</i>	<i>To be asked in all phases</i>
<ul style="list-style-type: none"> <li>• Provide access as early as possible through multiple channels</li> <li>• Support different approaches to learning</li> <li>• Support caregivers and their specific needs</li> <li>• Ensure consistent information across components</li> <li>• Use plain language</li> <li>• Speak to patients and caregivers directly</li> <li>• Time information appropriately to support understanding</li> <li>• Build reinforcement of components into the overall patient experience</li> <li>• Reinforce the relationship of components within the learning program</li> <li>• Provide components in different languages</li> </ul>	<ul style="list-style-type: none"> <li>• Have you heard of the Healing Hearts Learning Program?</li> <li>• When did you first hear about the Learning Program?</li> <li>• Which of the components of the Learning Program have you had a chance to go through?</li> <li>• Did you find that information in one place was also available in another part of the Learning Program?</li> <li>• Did you find the language easy to understand?</li> <li>• Did you find the information easy to understand?</li> <li>• Did the Learning Program give you the information you think patients and caregivers need?</li> <li>• Have you had a chance to tell patients and caregivers about the Learning Program?</li> <li>• What part of the Learning Program have you referred patients to?</li> </ul>
<b>Patient Experience Map with About Me Pages</b>	
<ul style="list-style-type: none"> <li>• Highlights key moments in the PPATH program experience including what is going to happen in the hospital and at home</li> <li>• Describes learning program components and how/when to access them</li> <li>• Provides opportunity for patients and caregivers to share information, about themselves, with providers</li> <li>• Can be carried from hospital to home</li> <li>• Uses visual illustrations to describe the experience moments</li> </ul>	<ul style="list-style-type: none"> <li>• Have you heard of the Patient Experience Map?</li> <li>• Did you find the Patient Experience Map accurate and useful?</li> <li>• Did the Patient Experience Map help you help patients and caregivers know what was going to happen in the hospital and at home?</li> <li>• Have you used the Patient Experience Map to guide patients and caregivers to other parts of the Learning Program?</li> <li>• Have you seen patients and/or caregivers using the Patient Experience Map in the hospital and at home?</li> <li>• Have any patients or caregivers showed you the About Me section in the Patient Experience Map?</li> </ul>

*Table 3 continues on the following page.*



Table 3, Cont.

KEY ELEMENTS OF THE LEARNING PROGRAM	SAMPLE QUESTIONS IN SURVEYS (health care providers)
<b>Patient and Caregiver Heart Surgery Education and Recovery Tips Brochure</b>	
<ul style="list-style-type: none"> <li>▪ Brochure renamed to <i>Patient and Caregiver Heart Surgery Education and Recovery Tips</i> brochure</li> <li>▪ New section added for caregivers addressing their specific needs and topics as outlined by caregivers</li> <li>▪ Creation of online version that is searchable; not just a static PDF</li> <li>▪ Photography reflects a broader patient group, including younger ages and diversity</li> <li>▪ Include photos of equipment needed in the home</li> <li>▪ Address topics outlined as most important for caregivers and most important for patients</li> <li>▪ Address the situation of patients who do not have caregivers</li> <li>▪ Reinforce where information in the brochure is available in other formats, such as the Healing Hearts Video Series or Discharge Class</li> </ul>	<ul style="list-style-type: none"> <li>▪ Have you had a chance to read through the <i>Patient and Caregiver Heart Surgery Education and Recovery Tips</i> brochure?</li> <li>▪ Did it seem that it was prepared with the patient and caregiver in mind?</li> <li>▪ Did you find the brochure accurate and useful for patients and caregivers?</li> <li>▪ What topics in the brochure have you found of most interest to patients and caregivers?</li> <li>▪ Were there topics that weren't in the brochure that should have been?</li> <li>▪ If the topics weren't in the brochure, could you help patients and caregivers find them in other parts of the Learning Program?</li> </ul>
<b>The Healing Hearts Video Series</b>	
<ul style="list-style-type: none"> <li>▪ Accessible in both hospital and at home</li> <li>▪ Address topics as outlined by patients and caregivers as most important</li> <li>▪ There are separate patient/caregiver-led and health care provider-led videos for each topic</li> <li>▪ Patient/caregiver-led videos are conversational and approachable, using real-life experiences and plain language</li> <li>▪ Videos are short; less than 2 minutes</li> <li>▪ Patient and caregiver-led videos are filmed in a non-clinical environment</li> <li>▪ Videos are available on a dedicated TV channel in the hospital</li> <li>▪ Videos are available through a website and/or mobile application</li> </ul>	<ul style="list-style-type: none"> <li>▪ Have you heard about the Healing Hearts Video Series?</li> <li>▪ Have you seen any of the videos in the series?</li> <li>▪ Where did you see the videos?</li> <li>▪ What videos would you think are most useful to patients and caregivers?</li> <li>▪ Were there topics that you think there should be a video on?</li> <li>▪ Did it seem that the videos were prepared with the patient and caregiver in mind?</li> <li>▪ Were the videos too short, just right, too long?</li> <li>▪ Do you think the videos featuring patients are relevant to them?</li> <li>▪ Do you think the videos featuring caregivers are relevant to them?</li> <li>▪ Do you think the videos featuring health care professionals are relevant to patients and caregivers?</li> </ul>

Table 3 continues on the following page.

**Table 3, Cont.**

KEY ELEMENTS OF THE LEARNING PROGRAM	SAMPLE QUESTIONS IN SURVEYS (health care providers)
<b>Discharge Class</b>	
<ul style="list-style-type: none"> <li>Provide more class time options on different days and times of the day, including evenings</li> <li>Balance 'lecture-style' learning with more time for questions and discussion</li> <li>Provide real life examples and scenarios shared by the Healing Hearts Volunteer</li> <li>Increase awareness about the class and when it is being held</li> <li>Create a video recording of the discharge class for viewing online</li> <li>Inform patients and caregivers before surgery, when possible, of the days and times the discharge class will be held</li> <li>Inform patients and caregivers before surgery, when possible, that there is an online video of the discharge class</li> <li>Direct patients and caregivers to other components where more information on the topics shared in class is available within the learning program</li> <li>Focus the discharge class topics to reflect those identified by patients and caregivers</li> </ul>	<ul style="list-style-type: none"> <li>Have you heard about the Discharge Class?</li> <li>Do you know what topics are covered in a Discharge Class?</li> <li>Did you know there is a version of the Discharge Class online?</li> <li>Have you seen the online version of the Discharge Class?</li> <li>What parts of the Class do you think are useful to patients and caregivers?</li> <li>Are there topics that you think should be covered in the Class?</li> </ul>
<b>Healing Hearts Website and Mobile App</b>	
<ul style="list-style-type: none"> <li>Content is consistent with content the <i>Patient and Caregiver Heart Surgery Education &amp; Recovery Tips</i> brochure</li> <li>Visually prominent link to the Healing Hearts Video Series</li> <li>Include an interactive version of the Patient Experience Map</li> <li>Include all necessary contact information, including the 24/7 hotline, Integrated Care Coordinator and Cardiac Surgeon's office</li> <li>Integrate exercise and walking programs</li> <li>Provide feedback to patients on exercise and walking program progress</li> <li>Include a Q&amp;A section and place to ask questions</li> <li>Integrates pre-op information</li> <li>Include information about rehab programs and relevant area supports (e.g. pharmacies that are close by)</li> <li>Have clear navigation that is easy to use</li> </ul>	<ul style="list-style-type: none"> <li>Have you heard about the Healing Hearts website/mobile app?</li> <li>If so, how did you hear?</li> <li>When?</li> <li>Have you referred patients and caregivers to the Healing Hearts website/mobile app?</li> <li>If not, why not?</li> <li>Have you been on the Healing Hearts website/mobile app?</li> <li>If so, was it easy to use?</li> <li>What parts of the Healing Hearts website/mobile app do you think would be most useful to patients and caregivers?</li> <li>Are there topics that you think patients and caregivers should be able to see on the Healing Hearts website/mobile app?</li> <li>Did it seem that the Healing Hearts website/mobile app was prepared with patients and caregivers in mind?</li> </ul>