

Purpose of This Report

The purpose of this document is to provide a final report for Phase 2 of the Room 2 Room Program.

Background

The Room 2 Room Program (R2R) was developed with the purpose of extending the delivery and accessibility of Room 217's benefit-designed music resources to people who are dying and their caregivers in Hospice Palliative Care programs and facilities across Canada. Hospice Palliative Care is one of the most vulnerable care sectors in Canada as well as one of the least funded. R2R provides an opportunity where funding to utilize Room 217 music resources in care is removed as a barrier.

Proposed Outcomes of the Program

1. The Room 2 Room Program will raise awareness of the importance of music in care within organizations and facilities that provide hospice palliative care.
2. The Room 2 Room Program will increase the sustainable application of benefit-designed music to improve quality of patient care for people who are dying in Canada by:
 - improving quality of life
 - assisting in relationship completion
 - decreasing feelings of isolation and fear
 - helping to meet psychosocial and spiritual needs
 - providing distraction from pain

Phase 2 Intentions

R2R Phase 1 was completed in June, 2013, impacting forty-one hospice palliative care facilities and programs across Canada. Phase 2 began in the fall of 2013. The intentions of Phase 2 are:

- to increase the means of music care delivery through technology (i.e. introduce the Room 217 music collection on an iPod shuffle, and test effects of delivery method in the HPC setting)
- to increase the kinds of HPC programs and facilities that receive Room 217's music care resources (i.e. hospital palliative units, dedicated palliative programs in large LTC settings).

Funding of the Program

With the receipt of \$25,000 in funding to support a second phase of the Room 2 Room Program, it was identified that fifty organizations/facilities would be included as program participants. Program participants were offered the option of three different music care Kits. Two of the three Kits in this phase included pre-loaded iPod shuffles as part of the package. We anticipated 40-50% of the facilities requesting technology-inclusive kits, while in fact 91% of participants requested technology-inclusive kits. This was not anticipated on our part and has increased the cost/Kit as the technology-inclusive kits cost more to deliver. This in turn reduced the number of organizations/facilities that could be included in the Program.

Accountability

R2R is designed to be a controlled delivery and support process as opposed to a giveaway program. The budget includes the cost of initial support, outcomes measurement and oversight and communication. Phase 1 of the R2R program provided Music Care Kits to forty-one HPC organizations/facilities. In Phase 2, the aim was to engage 50 organizations and facilities in the R2R Program. In reality, due to the high demand for iPods, only forty-two organizations/facilities were included in the Program.

Promotion of the Program

Initial Promotion of the Program

- Contact was made with organizations and facilities who had expressed interested in Phase 1 but were unable to participate due to human resource issues and/or the timing of the Program.
- Emails and phone calls were utilized to make initial contact with a list of potential participants.
- Phone calls were made to potential participants to screen for appropriate involvement in the Program.
- Contact was made with potential participants at the Hospice Palliative Care Ontario conference in April 2013 as well as the Canadian Hospice Palliative Care conference in October 2013 via the Room 217 exhibit.

Communication with Program Participants

- An introductory letter was distributed to participants as an inclusion with each R2R Music Care Kit.
- Follow up contact was made when resources were received by the participating program/facility.
- Follow up was made with Program participants once a month for a period of four months after the Kit was received. This communication was completed by phone call or by email (determined by the availability and choice of the program participant). The

Program Facilitator was available to respond to any questions or concerns raised by Program participants.

- Email communiques were distributed to Program participants to make them aware of the Room 217 music care education programs available to access.
- A submission to the Room 217 blog was completed in January, 2014. A R2R findings summary was included in Room 217's 2013-2014 Annual Report to Donors.

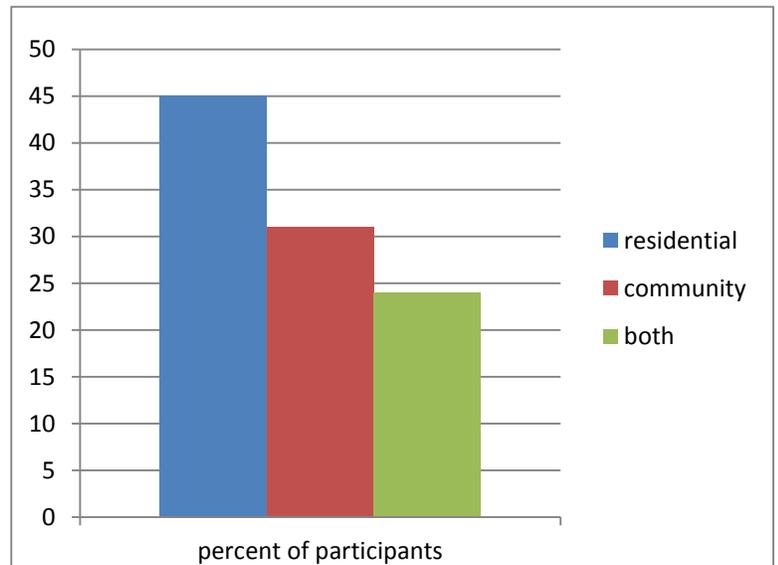
Hospice Palliative Care Program/Facility Acceptance

Each program/facility was screened during a telephone call between the Program Facilitator and an identified contact. After acceptance as a Program participant, organizations/facilities were asked to identify an R2R champion. This champion was responsible for 'overseeing' the utilization of the music care resources in the development or enhancement of a music care program within the hospice palliative care program/facility. Champions were asked to complete a pre-program questionnaire through an online survey.

Participant Profile for Phase 2 of the R2R Program

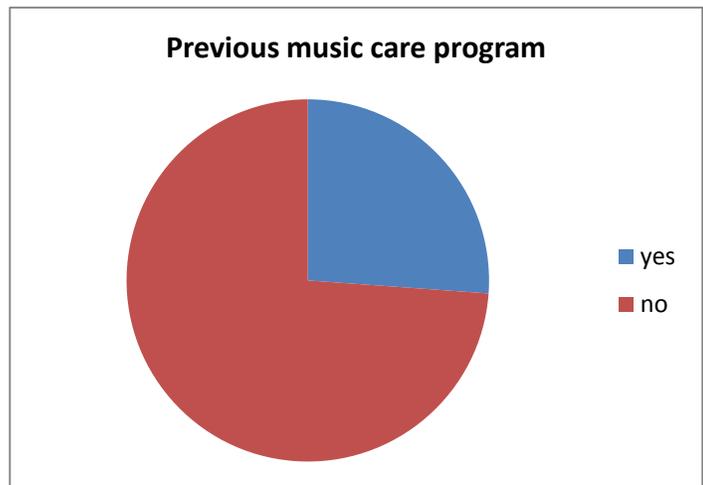
The type of HPC programs invited to participate in the R2R Program was expanded to include hospital palliative care units and long term care homes.

- 45% of participating programs/facilities were residential facilities – this included residential hospices, palliative care units or units contained in a long term care facility.
- 31% of participating programs/facilities were community based hospices.
- 24% of participating programs/facilities offered both residential and community based programs.



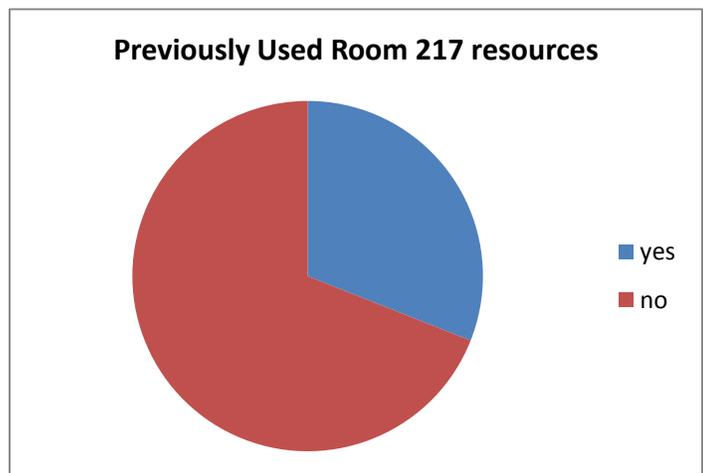
In the pre-program questionnaire, participants were asked about the existence of a music care program before participating in the R2R Program.

- 26% of participating programs/facilities already had some form of a music care program.
- 74% of participating programs/facilities did not already have some form of a music care program.



In the pre-program questionnaire, participants were asked about their use of Room 217 resources before participating in the R2R Program.

- 31% of participating programs/facilities had already used or were currently using Room 217 Music Care Resources.
- 69% of participating programs/facilities had not used or were not currently using any of the Room 217 Music Care Resources.



Enablers and Barriers for Program Participation

As potential participants for the program were invited to participate in Phase 2 of the R2R Program, a number of enablers and barriers were identified.

Enablers

- Familiarity with Room 217 music resources.
- At least one individual in a leadership role with an interest in music care (even if no current program existed within the organization).

- Leadership support of participation in a 'new' initiative.
- A strong volunteer base.
- Single layer of approval required before agreeing to participate.
- At least one person supported to champion/lead the implementation of the resources.

Barriers

- Concerns about the time and human resources required to develop or enhance an existing music care program.
- Concerns about the time and human resources required to participate in the evaluation of the project.
- Some organizations were unable to 'free up' a staff member to provide leadership to the program. It was identified that staff were already stretched beyond what is normally expected for their position within the organization.
- Multiple layers of approval required before agreeing to participate.
- Development of other programs or a focus on another initiative was considered a priority at the current time. The timing of the Program did not fit with the goals of the organization for this fiscal year.
- Leadership changes within the organization so the timing of this opportunity was not ideal for the organization as a whole.
- Minimal understanding of the value of music care in the provision of hospice palliative care.
- Commitment to actively engage others in the use of the resources along with other competing priorities.

Evaluation of the Program

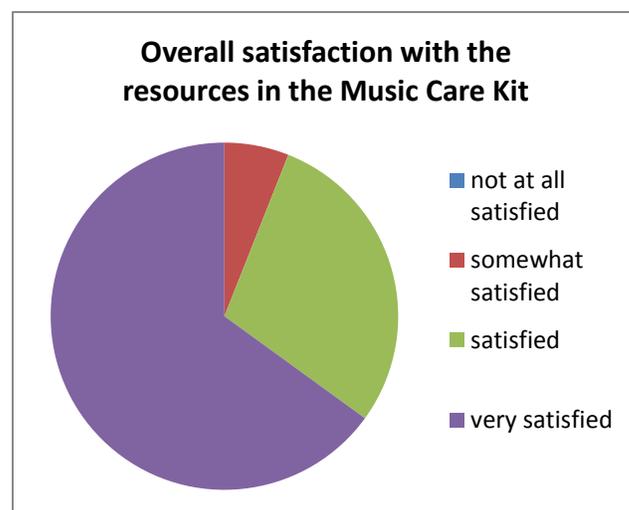
In addition to completing the pre-program questionnaire, all of the participating organizations completed a follow up evaluation survey three to four months after receipt of the Room 217 music care resources. Regular contact was made by the Program Facilitator to elicit feedback and to address any questions or concerns during the implementation of the music care resources during the project phase. Each organization/facility was required to provide the minimum of a monthly update to the Program Facilitator.

In order to establish the continuity of the R2R program and its ongoing benefits, participants from Phase 1 were asked to complete a short online survey in the spring of 2014.

Summary of the Post Program Questionnaire

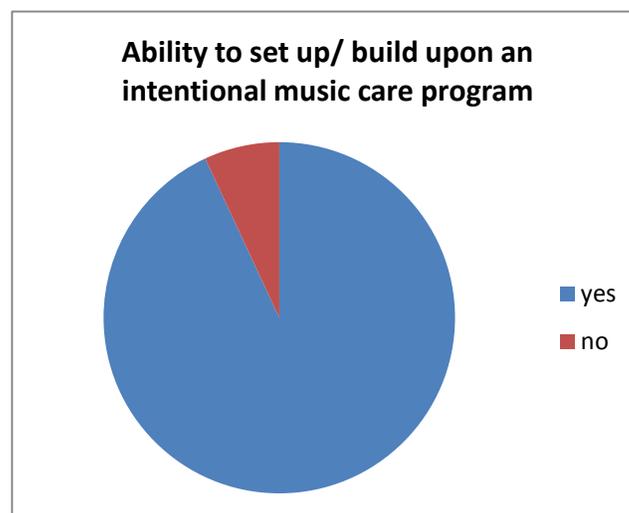
Program participants were asked to identify their overall satisfaction with the resources provided to them in the Room 217 Music Care Kit. 65% of participants were very satisfied with the resources they received. Comments included:

- “I am very impressed with the resources that we received. Before Room 217, we had no resources. We knew that this was a gap that needed to be filled in our regional program. Our palliative care program did not have the resources to hire an individual with expertise to fill this gap in our service. Room 217 was easy to implement by a palliative care team with not a lot of musical talent.”
- “The Kit was extensive and easy to use. We found the resources very helpful in providing comfort and relaxation during the often difficult end-of-life journey.”



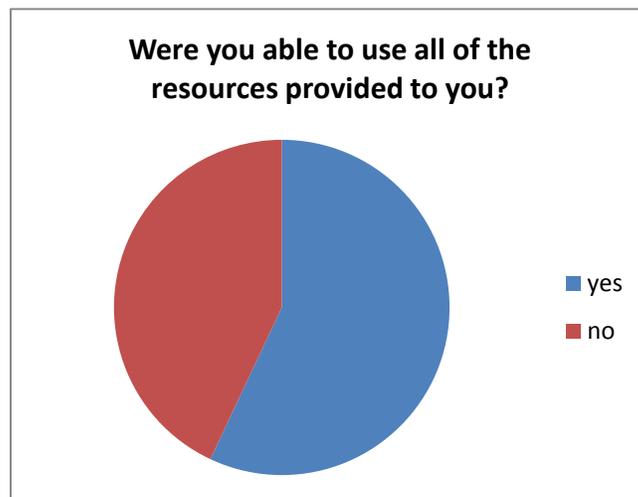
Program participants were asked if the Room 217 music care resources supported them in setting up or building upon an intentional music care program with individuals in their care. 94% of respondents indicated that the resources supported the development or enhancement of a music care program. Comments included:

- “Motivated us to make music therapy a priority for our palliative care program with the goal of enhancing patient comfort and symptom control.”
- “We were struggling with how to start and the timing of the Program was perfect.”



Program participants were asked if they were able to utilize all of the Room 217 resources provided to them in the Kit. 58% of respondents identified that they were using all of the resources. 42% of respondents indicated that they were not able to use all of the resources. Some of the barriers identified in using all of the resources included:

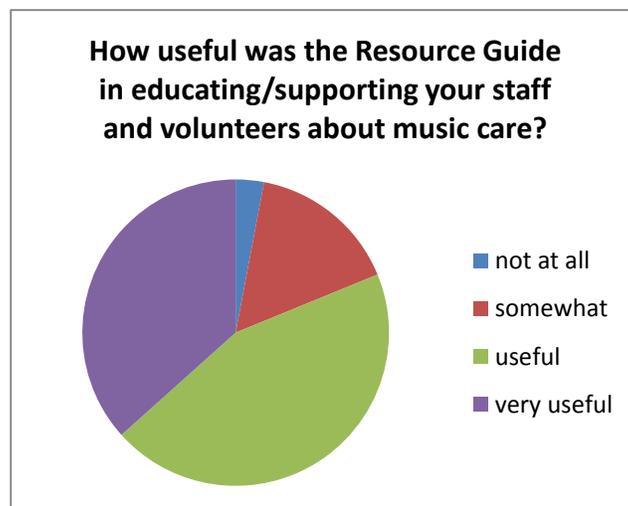
- “Obtaining adequate equipment to play the CDs was challenging”
- “Engaging staff to recognize the value of music care in supporting individuals in their care. Staff reluctant to become engaged in using music care identifying time as a limitation”
- “The time required to ‘teach’ individuals how to use the iPods”
- “Having a dedicated lead/champion was very helpful in implementing the use of the resources”



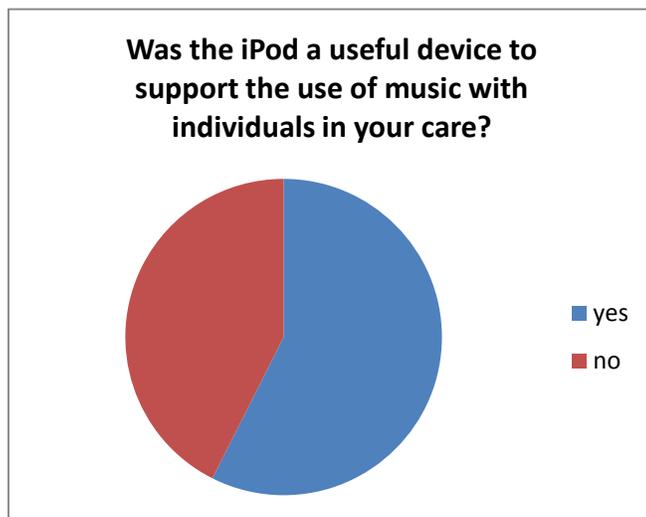
Program participants were asked if the Resource Guide: “Musical Approaches in Caring Communities” was a useful tool for educating and supporting staff and volunteers about music care. 81% of participants felt that the Resource Guide was very useful/useful.

Respondent comments:

- “Excellent tool to educate staff on music care”
- “Very useful resource to support the development of a music care program”



To increase the means of music care delivery through technology, the Room 217 music collection was added to an iPod Shuffle for Phase 2 of the Program. Program participants had the option of choosing a Kit that included a couple of pre-loaded iPod Shuffles. 91% of the Programs and Facilities opted to use this technology in the provision of Room 217 music. 58% of respondents indicated that the iPod was a useful device to use in the delivery of the Room 217 music care resources. Respondents identified a number of challenges in incorporating the use of an iPod to deliver the Room 217 music care resources to individuals in their care.



Using an iPod Shuffle: Pros and Cons

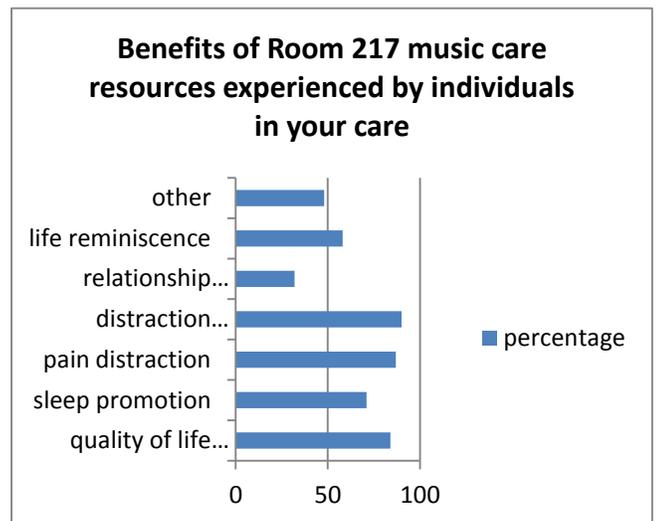
Participants identified the following pros and cons to using iPod Shuffles in the delivery of the Room 217 music care resources.

Pros	Cons
Allowed individuals to enjoy music in a shared room	Uncomfortable headphones
Useful for individuals who are hard of hearing	Infection control concerns Needed to develop polices for appropriate cleaning of device and headsets
Supported independence of individual to change a music selection without a staff member present	Loss issues: iPods are small and easily lost in bed linens and laundry; easily taken from the bedside
Very useful 'tool' in the management of behavioural issues - acted as a distraction	The technology was a barrier for some individuals (patients/family members and staff)
	Cost of replacing headphones a barrier to using the iPod

Participants were asked to identify the benefits of the Room 217 music care resources that were experienced by the individuals in their care (this included family members and caregivers). Distraction from pain, distraction from other symptoms and enhancement of quality of life were identified as the most commonly experienced benefits.

Additional benefits that were identified included:

- “Staff enjoy the ‘company’ of the music when caring for non-verbal patients”
- “Observed reduction in delirium and agitation”
- “Supported a calm and peaceful atmosphere for the family member(s) sitting at the bedside”



Experience of the Patient and Caregiver

Patients and caregivers were given the opportunity to provide feedback about their experience using Room 217 music resources.

- “Music playing in the background added to the sense of peace and quiet in the house”.
- “The quiet music was a great help in assisting the client fall asleep. The family member also found the music comforting and peaceful.”
- “My client has sleep disturbances caused by her pain, so she often wakes up during the night. However, the music has helped to reduce her pain episodes. Her stroke has impaired her speech, so music is also a good medium for interacting with her.”
- “One patient had become agitated, frequently calling out and restless when in bed. Having the CD’s playing in the room for long periods of time was a wonderful distraction and reduced his calling out and restlessness.”
- “For some staff, television tends to be used during down times for the patients. Since receiving the R2R program, that has shifted in part to utilizing the music instead. This has been a wonderful change as music is much more engaging and impactful for the patients than the use of television.”
- “The majority of our pediatric patient population have severe special needs and the music resources have helped on numerous occasions to calm them down. They may have been upset or just high energy and the effect of the music is almost instant to calm and relax them.”

- “The nurses have been playing music while providing personal care to patients who are unresponsive. They have found that the music fills the quiet space in a comforting and reflective way”.
- “One of the confused patients that we used the iPod shuffle and headphones on had been climbing out of his bed and was very restless. After sitting with him for a few minutes he began to settle, eventually falling asleep approximately 2 hours later. It was the first time he slept in the 36 hrs.”
- “Family found it helped in promoting reminiscing while sitting at the bedside with patient.”
- “It really dissipated the feeling that “something must be done” and replaced it with an ability for everyone to simply be present with what was inevitably happening.”
- “Patient admitted with lung cancer, was very anxious and short of breath. Patient and family indicated that she liked to listen to gospel music. We set up CD player with ear phones and used Room 217 Peaceful Presence. The patient closed her eyes and immediately was calmer.”
- “It helped family and friends to know that there was a “presence” in the room, even if no one was there.”
- “Our BSO team (Behavioural Team) have used the music and iPods extensively for the past several weeks. They have reported great results with the music calming our residents during care and when up in wheelchairs. One gentleman in particular is extremely restless in bed. Once he is up in the chair they are using the iPod with some of his favourite music on it. Results can be seen within minutes. This gentleman has advanced dementia and his wife was struggling with visiting him because of his restlessness. She is now content to sit with him and hold his hand quietly while he listens to his music.”
- “One of our counselors has utilized the music as a very soft ‘background’ in a couple of her counseling sessions with anxious clients. She identified that this has assisted in providing an atmosphere of relaxation that has calmed clients considerably.”
- “Our client told me that when she is listening to the CD’s her pain lessens. Sometimes she is able to enjoy some food while listening to the music.”
- “We have used the CD’s often with our infant and toddlers when it is time to rest and the older children when doing calmer activities (in place of a TV being on).
- “During a staff debriefing session, the music encouraged social interaction, helped them identify and express their feelings, evoked memories and gave them an opportunity to reminiscence and promoted comfort. Most importantly they began acknowledging their grief and found support in each other.”
- “A resident who was resistant to being toileted was less resistant when an iPod was used during this time.”
- “Music helped a person with a bipolar disorder sleep which in turn assisted in keeping his manic episodes under control.”
- “A reduction in the number of seizures in one individual was noted when an iPod was used.”

Opportunities for Improvement

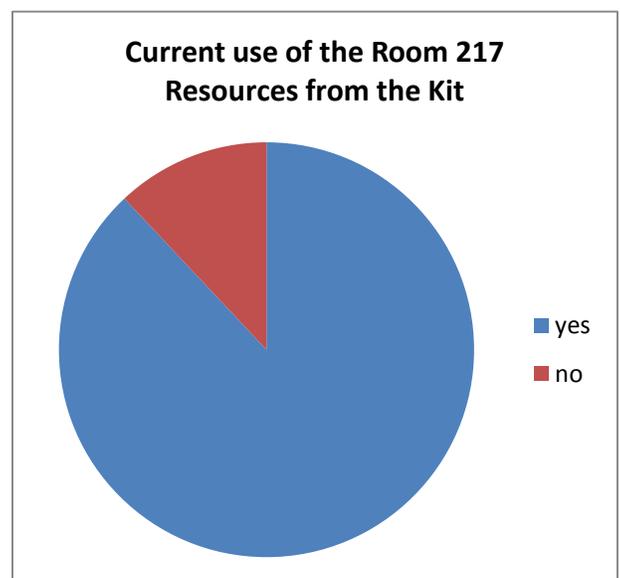
Program participants were encouraged to provide suggestions for improvement throughout the Program evaluation period. The following suggestions were received from Program participants:

- “Suggest the development of CDs with Indian, Chinese, Russian, Arabic, Spanish, Italian musical choices. There is not a selection of music that is of interest to or has meaning for individuals from the Asian communities.”
- “Would have liked more of the Classic Comfort CDs provided in the Kit as this was a popular choice.”
- “Would like to see more resources appropriate for children.”

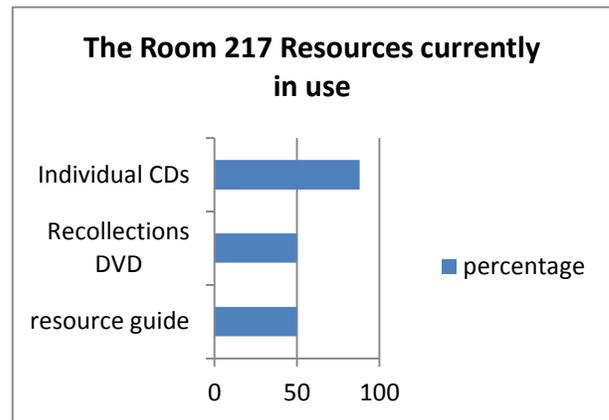
Follow Up With Phase 1 Participants: 1 year later

In order to establish the continuity of the R2R program and its ongoing benefits, participants from Phase 1 were asked to complete a short online survey in the spring of 2014. 26% of the Program participants from Phase 1 responded by completing the survey or provided feedback directly. Completing a 1 year post program survey was not part of the initial agreement with the Phase 1 participants. . This may have had an impact on the response rate to the survey. For 25% of the participating facilities/organizations, the identified champion for the program was no longer employed by the organization. A couple of organizations/facilities identified the challenge with accessing ‘survey monkey’ as their individual organization or facility blocks this website. Others may have experienced this as an issue but did not provide that feedback.

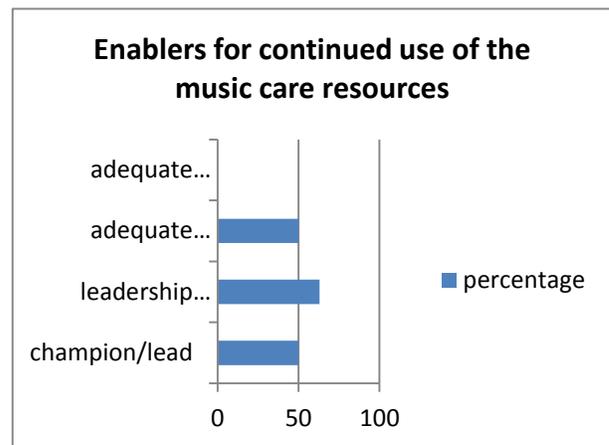
Of the respondents to the survey, 88% are currently using the Room 217 resources provided to them in the Music Care Kit.



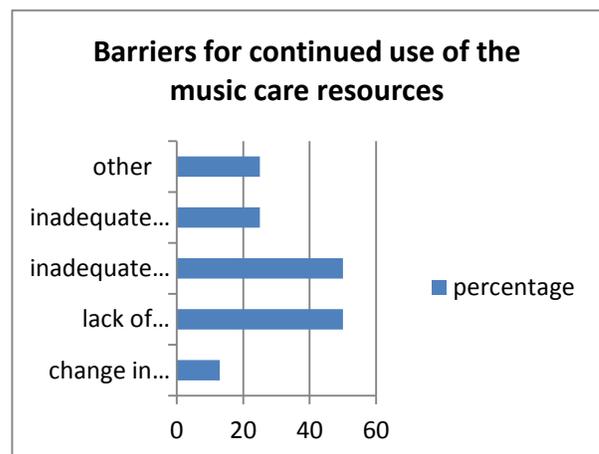
Program participants were asked to identify which of the resources they were currently using. 87% of respondents were using the individual Room 217 CDs. 50% of respondents were using the Recollections DVD as well as the Resource Guide.



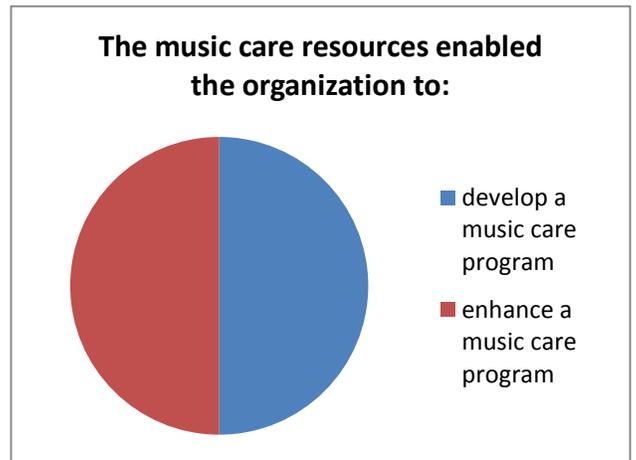
Program participants were asked to identify the enablers that supported the organization/facility in its continued use of the Room 217 Resources. 63% of respondents indicated that strong leadership support was key to the use of the Room 217 resources. An identified champion and adequate human resources were also instrumental in supporting the use of music care. One respondent felt that having a music therapist on staff was an asset.



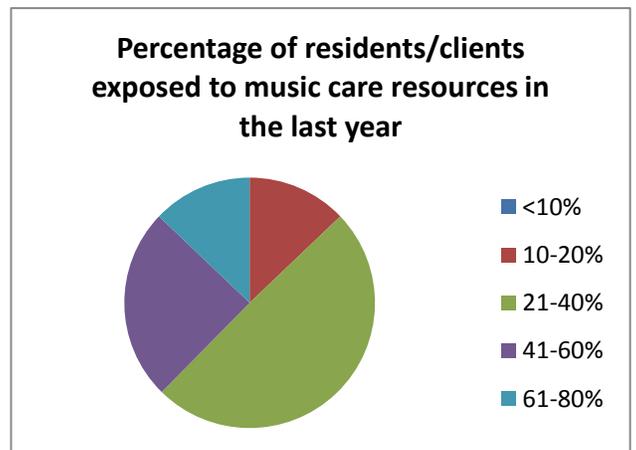
Respondents indicated that the lack of a champion or lead and inadequate human resources impacted on the ability to utilize the music care resources. An organizational merger was identified as a barrier for one of the respondents.



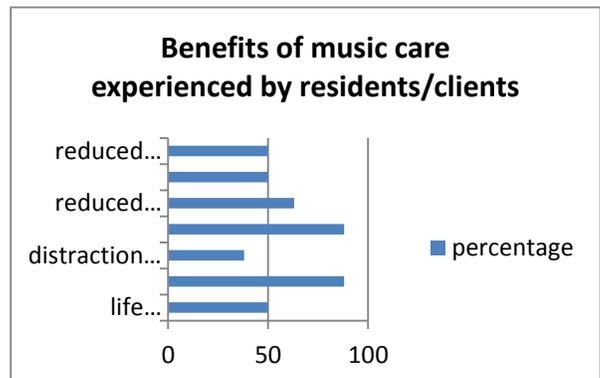
Participants were asked to indicate if after a year the resources enabled the organization/facility to develop a music care program. 50% of the respondents indicated that the resources allowed them to develop a music care program and 50% felt the resources allowed them to enhance an existing program. One respondent indicated that the Room 217 resources supported the facility's desire to offer music care to client's in the absence of a music therapist.



Participants were asked to identify the percentage of the residents/clients in their care that were exposed to the Room 217 resources in the last year. 38% of respondents indicated that >40% of individuals were exposed to the resources.



Participants were asked to identify the observed benefits of the Room 217 resources that were experienced by individuals. 88% of respondents identified reduced anxiety and distraction from pain as the primary benefits experienced. 62% of respondents suggested the residents/clients experienced less restlessness when they were exposed to the Room 217 resources.



Impact of Room 217 Music Care Resources: Emergent Themes R2R, Phases 1 & 2

The R2R program shows that Room 217 music resources impact patient care for people who are dying in Canadian hospice palliative care programs and facilities in at least these five ways.

Improves quality of life by:

- Promoting sleep
- Adding a sense of peacefulness to the space
- Reducing agitation and restlessness
- Making eating enjoyable

Assists in relationship completion through:

- Release and closure
- Promoting presence even when no one was there
- Providing intimate space between caregiver and loved one/client

Decreases feelings of isolation and fear by:

- De-stressing caregivers
- Reducing anxiety
- Mitigating resistance

Helps to meet psychosocial and spiritual needs by:

- Providing comfort
- Enhancing communication through reminiscence
- Companionship on the journey
- Providing a backdrop for expressing grief and/or mutual support
- Supporting reflection and meditation

Provides distraction:

- From pain
- Through soothing relaxation
- By providing another alternative (i.e. instead of TV)

Summary

R2R Program participants indicated that having a music care kit supported their ability to offer music care where this was not previously possible. In the four month program evaluation period, common challenges were encountered by participants. This included the lack of a champion or lead to support the use of the resources as well as an adequate staffing complement to support the provision of music care in the facility/organization. The time to adequately engage staff and volunteers to be involved was also important for participants. These were common themes for participants in the post program one year follow up.

A number of participants were challenged in their ability to initiate the use of the Music Care Kit provided to them. The timing of receipt of the Kit was a key factor in their ability to implement the use of the resources. Most Hospice Palliative Care Programs encountered challenges implementing the Program if the Kit was received close to the Christmas season due to competing activities during this time of year. Many of the organizations did not feel that four months allowed them enough time to expose staff and volunteers to music care and to the Room 217 resources before using in practice.

During Phase 2, Program participants had the opportunity to engage in a number of new educational opportunities offered by Room 217. The organizations that were able to participate in the webinars felt that they were very informative and increased their knowledge of music care. This supported their understanding of incorporating music care into the care provided to residents/clients.

The R2R Program was successful in extending the delivery and accessibility of Room 217's benefit-designed music resources to people who are dying and their caregivers in Hospice Palliative Care organizations and facilities across Canada. The Program created opportunities for organizations and facilities to offer Room 217 resources in the development or enhancement of a music care program in both phases of the Program. This was facilitated by the provision of resources at no cost to Program participants. The benefits of the Room 217 resources in the offering of music care improved the experience of the patient (including the family and other caregivers). The patient experience was improved through an enhanced quality of life. Distraction of pain and other symptoms was facilitated. Feelings of isolation and fear were reduced. Individuals and families were supported in the creation of opportunities for relationship completion.

Recommendations for a final phase of the R2R program

Based on the findings of Phase One and Phase Two of the Room to Room Program, I would recommend the following:

- Extend the time frame to support a longer evaluation period. This would support participating organizations and facilities the opportunity to adequately engage care providers to be involved. Would, for example, a 6 month evaluation period give more time for staff to feel prepared to use the resources?
- Support participating organizations/facilities with a webinar that would serve to introduce music care and the Room 217 resources. This would enable organizations/facilities to have a better understanding of how to maximize the use of the resources within the care setting.
- Extend the inclusion criteria for organization and facilities to include community support agencies i.e. nursing agencies who do palliative home care.