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‘Heart’ Arts in cancer-care pilot project

Evaluation Report

February 2015.

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1. Introduction & Background.

1.1 Project Background

In 2013, Darwin-based community arts worker, Fiona Carter, applied for and won a Commonwealth Government Regional Arts Funding grant to develop, implement and evaluate an arts-in-health program at the Alan Walker Cancer Care Centre (AWCCC). The program was called **'Heart'- Arts in Health**, and the grant was auspiced by Corrugated Iron Youth Arts. The 12 month pilot program began in February 2014, and continued through to February 2015.

'Heart' provided opportunities for people undergoing cancer treatment (eg. chemotherapy and radiotherapy) at the AWCCC to participate in a range of diversionary arts-activities such as music, visual arts, crafts, creative writing and video making. All activities were facilitated by skilled and experienced community artists. Some activities were brief 'one-off' workshop sessions involving two or three hours of activity. Others activities, such as the writing, animation and video making project (abbreviated to 'the film project'), involved engagement over several months

All activities (other than the writing, animation and video project) were based at the AWCCC. They were voluntary, free of cost and designed to provide much-needed diversion during treatment times. Activities were inclusive of patients' family and friends, and AWCCC staff if they wanted to participate. Because the longer term film project ended up become quite a different activity to those based within the AWCCC, these two aspects of the Heart project have been treated separately within this evaluation report.

Evaluation of the Heart project was undertaken to assess the effectiveness of the program, and to enable future planning for Heart, and similar arts-in-health care projects. Through undertaking evaluation interviews with AWCCC staff, arts-workers, patients and family members this evaluation provides a solid understanding of the Heart programs achievements, strengths and challenges.

Approval to undertake the Heart project at the AWCCC was obtained through Royal Darwin Hospital Management in January 2014. Approval to undertake the evaluation research was granted in July 2014 by the Menzies School of Health Research (the body which provides ethical consideration for all research undertaken with staff or patients in NT Department of Health services). The evaluation was funded by the original Commonwealth Government 'Regional Arts Funding' grant, and supported by the Research Centre for Health & Wellbeing, School of Health, Charles Darwin University.

1.2 Background to the topic of arts and cancer care

Research and evaluation literature about the use of various art-forms in cancer care has grown rapidly over the past decade. The most commonly reported arts interventions are music therapy (Aasgaard, 2001; Dvorak, 2011; Hilliard, 2006; O'Callaghan & McDermott, 2007; O'Callaghan, Barry & Thompson, 2012) and visual art therapy (Ando, M., Imamura, Y., Kira, H., Nagaska, T., 2013; Forzoni, Perez & Martignetti, 2010; Wood, Low, Molassiotis & Tookman, 2013). The literature demonstrates that, on the whole, there are positive associations between engagement with the arts and the improvement of cancer patients' mental health and wellbeing (Geue, Goetze, Buttstaedt, Kleinert, Richter, Singer, 2010). However, because every art-program involves different variables (e.g. type of art-form,

lengths of program, arts worker skills and experience, clinical setting, staff involvement, type and stage of cancer, age of participants) it is difficult to comprehensively assert that arts programs will provide benefits to the cancer patient participant. There is also a gap in knowledge about how these arts programs impact staff and the arts-workers themselves.

The evaluation of arts in cancer care programs has involved many different methodologies, formulated to answer specific questions about programs, from a range of viewpoints, and to complement the arts programs themselves. An evaluation of the Heart program is required in order to understand the benefits, challenges, strengths and weaknesses of the project, from multiple perspectives. Because the Heart program is a relatively small pilot program, with small numbers of participants, a qualitative evaluation framework has been selected.

Qualitative research allows for the exploration of meaning (Creswell, 2007). Qualitative methods provide a deep understanding of the strengths and challenges of programs through the lens of participant experience (Rogers & Goodrick, 2010). Interviews are used extensively for collecting qualitative data, and allow comprehensive exploration of particular events or phenomena (Travers, 2006). Focus group interviews are a particular type of qualitative interview method that provides opportunity for interaction between participants, generating reflective and responsive evaluation data. Focus groups involve small groups of people who are homogenous in some way (they have something in common), coming together in discussion about a particular topic with a skilled group facilitator (Krueger & Casey, 2010). Facilitated discussion between participants can help people 'unpack', explore and clarify views and ideas. As Kitzinger (1995, p. 299) argues, focus groups help us to 'examine not only what people think but how they think and why they think that way'. Individual and group interviews provide opportunities to gather rich data which can enhance understanding about the value and meaning of a particular program. They are also recognized as effective tools for exploring the value of arts programs (Knowles & Cole, 2008).

Because the Heart program was a new, small scale pilot program that has involved AWCCC staff, arts-workers, patients, and their families, it was appropriate to offer interviews and focus groups with participants from each of these four groups. The analysis of this information provides an exploration of the Heart program from a range of perspectives; allowing a solid understanding of the programs achievements, strengths and challenges.

2. Evaluation Summary

The Heart project was the first arts diversion program to be introduced into cancer care at the Alan Walker Cancer Care Centre (AWCCC) based at Royal Darwin Hospital, Darwin, Northern Territory. Heart incorporated a range of arts activities designed to provide much needed diversion from cancer treatment. The primary objectives of the 'Heart' project were to further enhance the holistic approach to cancer care delivery and improve the patient experience.

The aims of the Heart project *evaluation* were to:

1. Understand the benefits, challenges, strengths and weaknesses of the 'Heart' arts-in-health program, from the perspective of program participants and their families, AWCCC staff, and arts-workers involved in the program.
2. Explore the extent to which program objectives have been met.

The evaluation is presented in two sections. The activities based within the AWCCC are discussed first, and then the second part of this report focuses on the film project. In the first instance however, the evaluation results from both sections of the report are summarized here.

2.1 Evaluation Results summary

2.1.1. Activities based in the AWCCCC

- The **benefits** of the AWCCC based activities included positive distraction from cancer treatment for patients and staff, and an increased feeling of wellbeing in project participants immediately after the arts activity.
- The **strengths** of the project were the arts workers, the supportive context and the artistic products created.
- The **challenges** included engaging patient participants, determining the best structure and timing for the activities, and understanding what kinds of art worked best in the environment.
- The pilot project facilitated **new learning** about the importance of flexibility in project delivery, and the equal importance of process (that included conversation and observation of art creation) and product in the art making,

2.1.2 The 'writing, animation and video' project

- The major **benefits** for participants in the film project included mutual support, new learning, having a 'reason' and a 'plan', and being able to creatively express themselves.
- **Strengths** of the film project were the arts works and locating the activities outside of the AWCCC.
- **Challenges** were the lack project structure, lack of participant control over the final product, arts worker and participant anxieties, the complexity of animation as a story telling medium, and time and resources required.
- Much was **learned** about the size and composition of the group (no more than six people, scheduled after treatment and with a mixture of people with different diagnosis and prognosis). Balancing structure and flexibility, and ensuring that potential participants are personally invited to attend by their health care or support providers where also key learnings.

3. Evaluation Methods

A combination of individual and small focus group interviews were used to gain most of the data used in this report. Additionally, a simple 'smiley face' seven-point wellbeing scale was used to get a 'before and after' snapshot of people's feelings about the brief one-off arts activities.

3.1 Interviews

A combination of individual face to face interviews and two small focus groups (with two and five participants) were conducted by the evaluator using a range of open ended interview questions (Travers, 2006). The question guides are attached at Appendix A. Interviews were between 30 and 120 minutes in length. They were audio recorded, transcribed and thematically analyzed using a qualitative, general inductive approach (Thomas, 2006) to determine the major themes under each of the evaluation aim areas of: Benefits, strengths, challenges and new learning.

There were 12 participants in the individual and group interviews, drawn from the following groups

- Arts workers (5)
- Participants in the writing/animation and video project (3)
- Partner organization representatives(1)
- Heart project facilitator (1)
- AWCCC staff (1)
- Partner of patient participant (1).

3.2 Pre and Post arts activity 'feelings' scale

Five of the art/craft activity participants completed a 'before and after' seven-point scale. The scale was used to gain participant feedback about the craft activities impacts on wellbeing. Participants were asked to rate how they were feeling before the activity, and again after the activity. Simple descriptive statistics are used to display this data.

The results are presented in the following two sections of this report. The first section concerns the AWCCC-based activities. The second section concentrates only on the film project.

4. AWCCC Activities.

4.1 Description of activities based in the AWCCC

Over 2014, a range of arts activities took place within the AWCCC as part of the Heart project. Other than the Boab Mural and the art-exhibition, the centre-based activities were one-off activities which generally lasted for two to three hours. Each activity is described here.

Boab Mural

- A three-panel painting of a boab tree garden situated in the patient meeting room at the AWCCC.
- The mural was designed in consultation with a local artist, Linda Joy, the Heart project facilitator, staff and patients.
- As each patient completes treatment at AWCCC, they can write a message on a small boab leaf or nut and place it upon the mural.
- The mural will stay in place for at least the next two to three years.



Craft Activities

- Three sessions in total, facilitated by local artist Aly De Groot.
- One button/bead workshop (3 participants) and two silk scarf tie-dyeing workshops (5 participants each session).
- Workshops took place in the with chemotherapy treatment suite.



Music/Song Project

- Originally this project was to be collaboration between two young men whose father had cancer, and a local songwriter. However, for a range of reasons including some communication issues, this did not eventuate.
- In the end local musician, Dave Garnham, wrote a song about breast awareness.
- The song performed at a Breast Awareness display in Royal Darwin Hospital.
- The song was also audio recorded and can be used again by the Heart project team.

Art exhibition

- The original idea was to have a regularly changing or 'rotating' exhibition of local artists work in the AWCCC.
- This was to be a partnership between Darwin Visual Artists Association (DVAA) and Heart.
- Paintings from a local artist Brian Bully were hung in the AWCCC.
- There was a change in DVAA management and they were no longer able to participate. A new gallery has offered to take up this role in the future.

Biggest Morning Tea with Circus performers

- A circus themed morning tea was organised at the AWCCC.
- Corrugated Iron Youth Arts performers presented circus skills workshops.
- Raised funds and awareness of cancer.

The feedback about the centre-based activity has been summarized in the table below. Further detail about each section follows on from this. The data has been analyzed and presented using the five headings directly reflecting the evaluation aims. That is, the benefits of the program, strengths, and challenges, as well as new learning, and ideas for the future.

4.2 Overview of AWCCC based activity evaluation results.

Area	Themes	Sub Themes	Examples
Benefits	A positive distraction	Enjoyable and interesting for patients, staff and workers.	<i>I've since spoken to people that have seen the mural and that are going through treatment and they can't wait to write their little message on the little leaf. And it's sort of like that step, that you're going to be actually writing a story on this board, it's a beautiful thing. (Arts worker)</i>
		Enlivened the space with creative activity and beauty.	
		Provided different people (artists) to talk to about different things.	
		A sense of hope.	
	Increased wellbeing	Self-reported increase in feeling of wellbeing in craft activity participants.	<i>You made my day! (Patient participant)</i>

Strengths	The quality of the arts workers	They did their research.	<i>I think it's good to have the support that was offered from the staff and having the Heart facilitator and partners there. I think it's important to have that support– I couldn't imagine doing it by myself. I think it's important, they covered a lot of the things. You could just be an artist. So, it was good to have that, I think. (Arts worker)</i>
		They integrated new learning.	
		They interacted well with staff and patients.	
	A supportive context	Partner organizations.	
		AWCCC staff.	
		Flexibility in delivery.	
		Everyone was sensitive to the context.	
	Meaningful artistic outcomes	The boab mural.	
		Scarves.	
Challenges	Initial engagement of participants	Explaining workshops quickly	<i>I also found timing was a thing because everyone is at different times. Some people were interested in participating, but they only had ten minutes of their chemo left and then they were out of there. So, I had to, sort of, explain that they'll need 45 minutes. (Arts worker)</i>
		Gaining trust	
		Getting used to working with people who are unwell.	
	Workshop structure	Best times, days and length.	
	Not all artworks work all the time	Some work viewed as 'quite dark'.	
New Learning	The importance of flexibility	Responding to participants	<i>We all knew that we had to remain flexible with expectations because we didn't know how people would respond to the idea or any of that sort of thing." (Partner Organisation)</i>
		Artist skills and availability	
		The needs of the AWCCC	
	The value of the process and the product	Talking, learning, observing.	
		Creating and having something beautiful.	
Ideas for the future	Review of other arts in health care (chronic illness, cancer care)		<i>It would be interesting to explore the idea of an artist in-residence or something that could happen without having to make things with people or for them but that you could somehow be working in the space and that they get to - with one hand - help you spool the wool or, you know, whatever it is that, you know, that you could-- somehow you can encourage people to join in on a process that way. (Partner Organisation)</i>
	Longer and more frequent workshops		
	Artist in Residence Program		
	Visual aids for quick engagement		
	Some activity based outside AWCCC.		

4.3 Results in Detail.

4.3.1 Benefits of the program

All evaluation participants highlighted benefits arising from the Heart program activities. Each of the benefits raised by participants is explored here, using their own words whenever possible.

A positive distraction

The Heart program activities were viewed by everyone as being 'enjoyable' and 'interesting'. Having the opportunity to learning something new was also an important aspect of enjoyment reported by patient participants, arts workers and AWCCC staff involved with the activities. The following quotes, from an arts worker and a patient, provide a clear overview of one activity and the 'delight' associated with it.

I explained the process and asked "would you like to do it?" Basically we were wrapping up the silk and making a little parcel. I would help so it didn't end up being too much of a big task. Then we'd have a big chat about art, or different sorts of things, or a memory would get triggered. They might just start talking about their family or "my daughter's an artist". Then, eventually, they'd have a finished product. I'd give it to them, and they loved it. There was a lot of joy in that regard because they've got a beautiful silk scarf that they could wear as well. (Arts worker)

Thank you, I am delighted, you made my day. (Patient Participant)

Enlivening the 'space' in the AWCCC was another benefit. Activities were not only for patients, and at times staff also actively participated in activities such as circus skills. As two participants describe it -

We had a couple of the circus kids going into the chemo suite and they played and that was good, the distraction, and the chance to talk to some kids. (Heart Project Facilitator)

It just enlivened the workplace. For the staff to suddenly have something positive and sparky in there is quite rejuvenating. Even if you're not participating, and then having the opportunity to join in. (Partner Organisation)

Bringing creativity and 'beauty' into the cancer care space was another way of enlivening the AWCCC. One arts worker describes how creating beautiful scarves enlivened the room.

Just joy, like "wow, that's really beautiful." And, they were surprised by the colours too, because I was using a wet season berry that is only out at that time of year. So, we were getting these really bright beautiful scarves, and the lime leaves. People seemed, just happy and grateful. (Arts worker)

Throughout the Heart project, artists and project workers took on the role of being 'different people to have different conversations with'. As the following participant quotes demonstrate, this variety of conversation and associated activity was important for providing much needed distraction.

"The conversation didn't revolve around your illness which, I've got to say when you've been treated for cancer, every conversation revolves around your illness and people often feel awkward when they come and sit with you, so you talk about the weather or your illness. So it was actually--to be able to talk about berries that flower or something or "What do the lime leaves do?" or it was actually great."
(Heart Project Facilitator)

It's about different people to speak to. The people who are always there are the medical staff whose job it is to have a medical conversations. So it's that opportunity to be distracted by something else. (Partner Organisation)

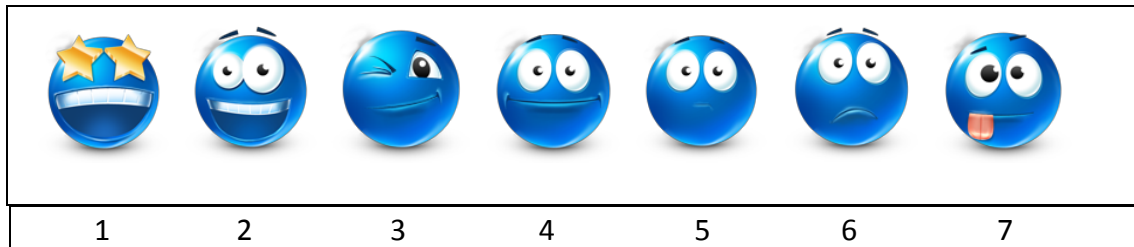
Four participants discussed the way the arts projects helped to create a sense of hope and 'something to look forward to'. The boob mural in particular was viewed as a small window into a future when people would complete their cancer treatment. The following quotes demonstrate the importance of the mural to patients and staff alike,

I've since spoken to people that have seen the mural and that are going through treatment and they can't wait to write their little message on the little leaf. And it's sort of like that step, that you're going to be actually writing a story on this board, it's a beautiful thing..... Someone told me that the mural gives hope. There is hope and all of these people that have got messages on the tree have gone through treatment and come out the other side. So, it lets you know that you're not alone
(Arts worker)

I think the Boob Garden Mural is amazing. It is such a beautiful piece of work, and it provides the patients an opportunity to take the time to reflect on what they have been through and signify each milestone. It's also a really lovely thing to do for our patients, as often we get to know people really well, and they will put a leaf on the mural with one of the nurses. I think this is really important for the nursing staff too..... I think the Boob Mural creates a private space where both staff and patients can reflect. (AWCCC Staff)

Improvement in participant feeling of wellbeing

A 1-7 scale where 1 means 'feeling great' and 7 means 'feeling terrible' was used to gain an understanding of whether there was any change in participants general feeling of wellbeing immediately prior to and immediately after participating in a arts/craft activity. The scale looked like this:

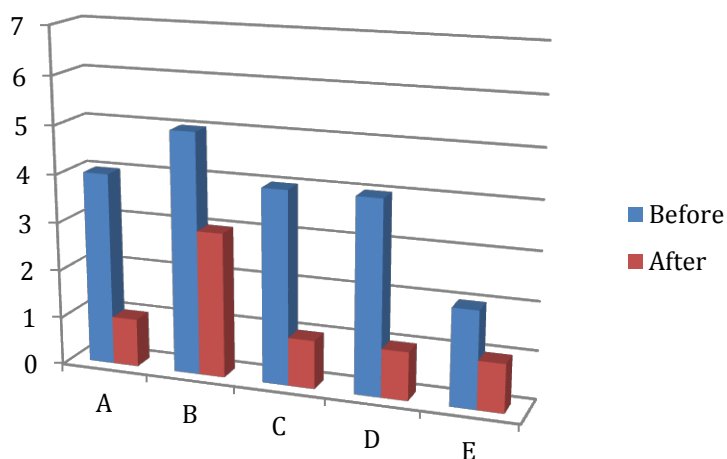


The results show that each of the five participants experienced a positive increase in their feelings of wellbeing.

	Person A	Person B	Person C	Person D	Person E	Averages
Before	4	5	4	5	2	4 (feeling average)
After	1	3	1	1	1	1.4 (feeling great – good)
Change	+3	+2	+3	+4	+1	+2.6

If the smiley scale is transferred to a numeric one, and each increment in wellbeing is given a weight of '1', we see a range of between 1 and 4 points of increased wellbeing, and an overall average increase of 2.6 points.

The chart below provides a pictorial representation of the same data. The horizontal axis is the participant, and the vertical axis is their wellbeing score. As noted earlier, the lower the 'score' the greater the feeling of wellbeing is, the chart shows a very clear increase in wellbeing in the pre and post survey.



Prior to the craft activity, 4 out of five participants reportedly felt 'average' (4) or 'a little below average' (5). After the craft activity, 4 out of 5 participants reported 'feeling great' (1), with one reporting that they felt 'a little better than average'.

4.3.2 Strengths

The quality of the arts workers

The arts workers engaged in the project were 'hand-picked' due to their artistic abilities as well as their ability to interact with a range of people in the specific cancer care context.

Arts-workers took their roles very seriously, with some doing research about cancer care prior to beginning, and also during their work for Heart. The following arts worker quotes demonstrate the commitment to this learning process.

I think that you really need to do your research and you need to put yourself in the space. (Arts worker)

It's quite a hectic process, the treatment, but through it they started to look forward to writing their story on this mural. I mean I spoke to probably six people. And I did do a lot of research, so I could actually rave on and on about that, but people do tend to reflect and all of those little things really do count. (Arts worker)

Arts workers also talked about integrating feedback from their practice into their work as it progressed. They discussed learning about working with people who were unwell, and exploring new types of therapy as part of their learning. The following quotes show some of this learning.

The first feedback I got, it was interesting because I've been making those silk scarves as a product in my art practice for a long time. But, the feedback I got back was "we would prefer big square scarves". I was using long ones at first. So, then I went and got some big square ones, so that was good feedback to make it more relevant for them to wear. (Arts worker)

I learnt a new word - diversional therapy. One of the nurses said something to one of the other nurses "She is here to do diversional therapy." So, I thought that sounds really interesting, I'll go home and Google what that actually is. And, I realised that it's what this project is. That creativity is a basic human right and it's providing opportunities for people, and so I've felt really happy to be a part of a project like that.I'd never even heard the word before, but I realise it's actually something that I've been doing for a long time, through sharing my art form. (Arts worker)

The Heart project facilitator and AWCCC staff reported that the arts workers integrated into the AWCCC space well. They 'fit in' and worked with the people and the situation nicely. As the Heart project facilitator discussed, "I was very careful with the artists I chose". This careful selection of suitable artists is reflected in the next quotes.

I knew Aly would fit. I knew with what she does she would fit. I knew with the sorts of people she's worked with in the past that she would. I just knew that she was the right person. (Heart Project Worker)

A supportive context

A major strength of the Heart Project activities at the AWCCC was the support received from partners (for example, AWCCC, Corrugated Iron Youth Arts, Darwin Visual Artists Association and the NT Cancer Council). AWCCC Staff were committed to the project from the outset and helped to facilitate its development and evaluation. The following quotes demonstrate the depth of commitment to the project, and highlight the value of partner knowledge and understanding. It is this commitment helped to facilitate the running of the project.

We could not have done it without Emma [Clinical Nurse Manager at AWCCC]. It would have been impossible. You'd need to have at least one person and one influential person in the medical facility that understands; that gets it. Not just understands it on paper but just really gets it. She totally gets it. You need to know the staff and I think as well, just the fact that I'd been through the situation. I understood what it was to be a patient in there and I sort of understood how it worked. (Heart Project Facilitator)

I think it's good to have the support that was offered from the staff and having the Heart Project workers there too. I think it's important to have that support– I couldn't imagine doing it by myself. I think it's important; they covered a lot of the things. You could just be an artist. So, it was good to have that. (Arts worker)

Some staff also took a very 'hands on' approach to showing their support, and embraced the opportunity to participate in an activity or two, as the next quote shows.

Jon spent quite a long time teaching some staff to juggle. There was one guy who was transfixed with the Diablo. He went away, he came back again and brought his other staff with him, and then they all wanted a photo. (Heart Project Facilitator)

The biggest morning tea - I actually think the benefit to staff was greater in this instance. I think that it gives the staff an outlet/fun at work, and the sense of really being a part of something great. (AWCCC Staff)

Because the project was a pilot, and involved an element of 'trial and error' in exploring what art forms worked and in what format, a large amount of flexibility was required. People readily accepted this need and worked to ensure that this could occur, as the following quote shows:

We all knew that we had to remain flexible with expectations because we didn't know how people would respond to the idea or any of that sort of thing. (Partner Organisation)

Throughout the project all parties remained sensitive to the AWCCC context, and tried to ensure that no patient felt 'hassled' or 'pushed' into any activity that was occurring. The arts workers and project workers were very definite that the project would not be intrusive for anyone not wishing to be involved. The next quote demonstrates this sensitivity.

We haven't had anyone go, "no, go away" – or "what are you doing?" Certainly not. We've been very, very sensitive to the fact that people might not feel very well or whatever and we absolutely briefed the artist that if someone says to you,

"Look, can you just go away," it's not personal. They just don't feel very well.
(Heart Project Facilitator)

Meaningful artistic outcomes

The actual 'end results' of the arts endeavors were viewed as meaningful, beautiful and useful. In particular the silk scarves and the boob mural were singled out for attention as the next two quotes show:

Aly did the work and people got to see this amazing result unfold and it was a beautiful thing that you could wear, give away, whatever was going to happen to it.
(Partner organisation)

I think the Boob Garden Mural is amazing. It is such a beautiful piece of work.
(AWCCC Staff)

I think it's [boob mural] invaluable, I don't think you can put a price on something like that (Arts worker).

4.3.3 Challenges

The pilot project faced a number of challenges in its delivery in the AWCCC space. These are discussed here under the major themes of 'introducing and engaging', 'workshop structure and scheduling', and 'not all art-works work'.

Introducing and engaging participants

In the chemotherapy suite based activity, arts and project workers found that it took some time to fully explain the activity being offered, to ensure people knew it was free and that they could refuse to participate, or to participate in any way that suited them.

Project workers reported that more people participated the second time they ran a workshop, and the arts worker and project worker actually approached people in a conversational way and invited them to participate. This was a different approach to the first session, where a health worker had spoken to patients, and perhaps had difficulty describing what it was all about. An arts worker and AWCCC staff member explain the issues in the first two quotes,

Getting people engaged the first time, it felt like, I think there were quite a few people that thought I was trying to sell them something! I feel like maybe there needed to be something that quickly explained the project, or some sort of ground work, because I felt a little bit like I was intruding in people's space. The reaction a bit was "how much?" (Arts worker)

I found it difficult to get a lot of patients involved. This is because of many reasons, new cancer diagnosis, feeling overwhelmed by treatment, feeling unwell. I think there are a lot of patients who are emotionally and physically very acute whilst undergoing treatment. And sometimes they may feel an added pressure by even being asked to participate. There was good take up by patients during the project, but it is variable. (AWCCC Staff)

As a result of engagement challenges, the arts and project workers attempted a different approach. This changed practice is reflected in the following quote:

“Rather than going up and saying, “We have this project,” and it was a bit of a thing off to the side, it was just like we just got chatting, “Hey, hello. I’m Fiona, I’m running this project and this is Aly, she’s an artist and, look, we’re just doing this thing. She’s making this. Do you want to have a go?” (Heart project facilitator)

The initial engagement could also be difficult for arts-workers who were new to the cancer care setting. Working with people who are unwell could be confronting, but ultimately rewarding, as the following arts-worker explains.

It was challenging -, yes because I’ve never really hung out with sick people. And yeah, to see people that sick. Yes – it’s sad. But, also rewarding to see them smile at the end or, you know, to see them smile at all. (Arts worker)

Workshop structure, scheduling

A challenge noted by project and arts workers was figuring out how to structure the AWCCC based activities so that they were open and accessible to the range of patients at the Centre. Patients were at different stages in treatment, and had different social supports and needs. As the Heart project facilitator explains.

Sometimes there are two people in the chemo suite, sometimes there’s ten, and sometimes you’re there every three weeks. Sometimes people are very sick. Sometimes they’re not. Sometimes people have visitors with them. Sometimes they don’t. It’s actually quite difficult to--it’s not like you’ve got a captive audience of ten people for three hours every day. You haven’t. (Heart project facilitator)

It was also important to schedule activities so there was enough time for patients to complete an activity. This proved difficult as the following quote demonstrated.

I also found timing was a difficult thing because everyone is at different times. Some people were interested in participating, but they only had ten minutes of their chemo left and then they were out of there. So, I had to, sort of, explain that they’ll need 45 minutes, have they got 45 minutes? (Arts worker)

Not all artworks/art forms work all the time

Art is subjective, and people will have differing views about artworks. In one case, an exhibition of visual art received some feedback that meant rethinking the type of work that was placed in the AWCCC. This is explained in the following story from the Heart project facilitator.

I spoke to a local arts organisation about doing a curated, regularly changing art exhibition. We basically said “once a month, we’ll put a different artists work in there,” because when you’re having chemo - and also for the staff - you go in every day. It means that every now and again the art work will change.The first art that was chosen – the artist is usually quite dark and I sort of wasn’t sure. The comment that’s come back from AWCCC was, “You know, a few of the staff actually said that they thought it was quite dark.” (which at least means they noticed it!). Then it sort of stopped because the arts organisation, the person I was dealing with

felt that it was just too much and they couldn't do it - which was fine - and I have now talked to a different gallery and they said, "Yeah, absolutely. We can do that".
(Heart project facilitator)

4.3.4 New Learning

Participants in this evaluation highlighted that they had learned much about arts in cancer care during this pilot project. The learning concerned the importance of flexibility and the value of *both* processes and product in the arts work.

The importance of flexibility

Flexibility was the key to 'making things happen' in this pilot project. Flexibility in art forms, and types of participation worked to ensure that the Heart project was able to respond to the AWCCC context as needed. For example, the first art/crafts workshop used buttons and beads to make jewelry with patients. However it quickly became clear that this was not going to work as expected because patients in the chemotherapy suite only had one hand free (the other being connected to an IV drip). Activities were then adjusted with this restriction in mind. The following quote from a partner organisation highlights that flexibility was needed in a range of ways, included when an artist was unavailable.

I think that openness and flexibility and responsiveness to the setting. They need to be ready for that from the outset and that that includes, what you do when the artist is sick and can't go and that sort of thing - be ready to change the activity. So when an opportunity arises or something's not working, that you shift. (Partner organisation)

The Heart project coordinator pointed out that the much-loved boob mural was a result of the project being flexible enough to take the views and ideas of AWCCC staff into account

And that's the flexibility. The Boob was never part of the original project. That was something that the Clinical Nurse Manager came up with." (Heart project facilitator)

The value of 'the process' and 'the product'.

While the arts activities in the AWCCC were initially intended as 'diversionary' there were extra benefits in both the process of creating the art work and in the art work itself. As previously explained (in the 'strengths' section) the art works, particularly the boob mural and scarves, were viewed as meaningful and beautiful in and of themselves. However the 'talking and learning' that occurred during the processes of creating the art were just as important.

Participants pointed out that it was good for patients and staff to have 'different kinds of conversations' with the artists and performers, even if they were not actually participating in the art-making. These conversations were not just about illness or treatment, but about many other aspects of life. An arts worker provides some examples in the following quote.

It was very light, very chatty, and they were really interesting, different people. There were a couple of people that didn't even want to participate in the activity. They were happy to just have a chat about art and about what I do or about art in general. There was one man in particular, he talked about his travels and different art he'd seen in museums and things.....People like to chat about the craft that they do, the knitting that they do, the different things that they like to make and stuff, and just have a general, nerdy, crafty, chat! (Arts worker)

4.3.5 Ideas for the Future

The following ideas were generated by evaluation participants for any future, similar arts diversion projects in the AWCCC.

Review of other arts in health projects in cancer care facilities

The learning from the Heart pilot project has inspired the project facilitator and other arts workers to learn more about what is happening in the arts-in-cancer care field internationally. Placing what has been learned in this pilot in an international context is considered important for creating strong, evidenced base arts and health practice in the NT into the future. The following quote emphasis the importance of learning more

I still like the fact that you can be distracted while you're in the chemo suite but I think that it needs much more work. We need to put a lot more thought into that and finesse with it. That's why now I would like to go and see other projects and see what they've done and how that might work. (Heart project facilitator)

Longer and/or more frequent workshop sessions

Feedback from patients to arts workers reveals that while patients liked the activity, they would appreciate more of it, so that patients and staff at AWCC where 'used to' the idea of their being an artist involved in the cancer centre, and so that there was continuity and follow up with patients and activities. An arts worker explains this in the next quote.

They loved it, and there was one woman in particular that was really keen and she wanted to do more, because it was her first, kind of, introductory session, and then I never saw her again. So, that was a shame because she was really keen and wanted to, you know, she had ideas of different things she wanted to make with me. So, that's probably one thing we can talk about later with regards to continuity. (Arts worker)

Making each actual workshop longer was also suggested as a way of ensuring more patients were able to access the art-making. Having some advertising or notices about the art workshops would also broaden awareness of the activities. The following quote provides some further detail about these and more ideas.

I'd probably make it longer. Be there for a whole day. Because, I didn't realise that there's people coming and going and they're there at different times. And maybe have some sort of advertising - like a big A3 laminated, sign that says 'Thursdays is art day', and I would probably, through that promotion, maybe try to engage family as well. Because, a few people said they were making gifts for their family. And so, if people knew it was a Thursday, then next Thursday they might

bring their daughter that maybe never usually comes with them, but then that can engage her too. (Art worker)

An 'artist in residence' program

The Heart project facilitator, partner organization representative, arts workers and AWCCC staff member agreed that an artist-in-residence program, integrating arts diversional work into the AWCCC space in a long term project, would be beneficial to explore. If an arts worker were based in the AWCCC, creating art and inviting patients, families and staff to observe, or join them in the creation, then patients would become familiar with the idea, and have time to explore projects together. This idea is explained in more detail in the following quotes.

It would be interesting to explore the idea of an artist in-residence or something that could happen without having to make things with people or for them but that you could somehow be working in the space and that they get to - with one hand [as the other hand may have an IV drip attached to it] - help you spool the wool or, you know, whatever it is that, -somehow you can encourage people to join in on a process that way. (Partner organization)

Everyone could build up a relationship within it, the artist and the art work. I think that's a fantastic idea because one of the things that's problematic is that the artist is a little bit nervous because it's a new environment to them. The staff don't really know who they are. The patients don't really know who they are. Whereas if you go in and right from the start, because you do an orientation, they sit you in the chair and they tell you what you're going to go through, and part of that orientation could be, "here's the artist". (Heart Project Facilitator)

Visual aids for quick engagement

Because engagement in chemotherapy suite activities needed to be fairly quick and easy to explain, one arts worker suggested that some visual aids, such as a booklet, photographs, posters or web-site, could be useful. The aids would allow people to see and understand what the arts focus is and what end-products might be. In this way people could see that it is part of the AWCCC activities on offer and not something 'being sold'. An arts worker explains the idea in the following quote.

I suppose people aren't used to getting something for nothing. So, I had to be quick to explain the project "I'm being employed as an artist to do this with you and it's free." It would have been good, I think, if there was some sort of visual aide. Maybe pictures from previous projects or something - because I think pictures are a lot more useful. Maybe a little booklet, or something. Or, just something so people could explain "this is a previous workshop that we have done and this is what people did. Would you be interested?" Maybe previous work or things hanging up or something that would make it more obvious what I was doing, I think it would engage people a lot more. (Arts worker)

More activity based outside of the AWCCC

Another suggestion was to have activities take place in locations other than the AWCCC. While the writing/animation/video project (discussed in the following section) was based externally, all other activities occurred at the AWCCC. Some people felt that a variety of locations would help to encourage people to continue creative activity they have been introduced to within AWCCC. Others felt that the AWCCC would be the best location for art that can be observed and discussed (e.g. in the waiting room, or chemotherapy suites), without too much 'doing' at a time when people are undergoing treatment. Other 'doing and making' activity could occur when people are more ready to engage, and at locations outside of the AWCCC. As the following staff member quote explains, the AWCCC could be a place to promote and invite people into projects.

I think that if these activities existed outside of the centre, it can also create a 'safe haven' for people, without a threatening environment. I think that AWCCC should certainly recruit and promote the programs to people within the centre, to attend within the community setting. (AWCCC Staff)

One suggestion for a host organization for such activity was the NT branch of the Cancer Council. The following quote explains this further.

"It would be good if something was run out of Cancer Council or something similar. ... Maybe it is more the craft activity or something that we could try running, that you can go to just one day in the week or something. You know, it's an activity that's run by us at a different place." (Heart project facilitator)

4.4 Summarizing the AWCCC based activities

In summary the AWCCC based were varied in their art form and approach. While staff joined in with the fun and action of the circus performances, it appears that patients most valued the Boab tree mural and watching the silk scarf creation. For the future then, activities that encourage patients to observe and converse about arts and crafts may be the most beneficial and useful for them. Centre based activities could act as a 'conduit' to more active and participatory community based arts and crafts activities. This brings us to the next section of the evaluation report, the writing, animation and film project, which had a stronger element of patient participation.

5. The Writing, Animation & Video Project

5.1 Description of the activity

The original idea for this project was to engage a group of young adults who were undergoing cancer treatment, in a six week writing and film making workshop. However, due to lack of participants that fitted this category, it was decided by all parties, to open up the program to whoever might like to participate. The Clinical Nurse Manager at the AWCCC invited participants who she felt were at a stage where such a project may be beneficial to them. The activity evolved as the three participants became involved. The writing workshops were facilitated by a local play wright, Mary Anne Butler. The resulting script was to be transformed into a short animated film by local animator and film-maker Huni Bolliger.

Most of the participants were new to script writing and some were reluctant to write at all at the outset. Without knowing where the project journey would end, the participants, along with Mary Anne and Huni, set out to discover more about writing, cancer and supporting themselves and others along the journey. Eventually six workshops were completed, and an 11 minute film was developed. The film contained a few minutes of animation inspired by the participant's discussions and writing activities. The film also contains participant's stories of their cancer journey and advice to others who may be facing similar experiences.

The information in this section of the report has come from a thematic analysis of the following data collected by the evaluator:

- Transcripts of individual interviews with an art workers and the Heart project facilitator, and written feedback from another arts worker.
- Transcripts from a two-hour focus group with all three patient participants, one family member, and the Clinical Nurse Manager, AWCCC.
- Email interview with Clinical Nurse Manager, AWCCC.

The interview and focus group questions are included in the Appendix.

5.2 Overview of the film project evaluation findings

The following table provides an overview of the evaluation results concerning the film project. The table has been organized using the evaluation aims as major 'areas'. The detailed thematic analysis that follows the table provides in-depth information about each of the areas summarized in this table.

Area	Themes	Sub Themes	Examples
Benefits	Support	Being with others who understood	<i>It's good to reflect on the journey without having to find any solutions. (Participant)</i>
		Sharing uncertainty	
		Survivorship – life goes on	
	Learning	About yourself	<i>It expanded my insight into the way I was doing things and the way I was thinking. (Participant)</i>
		About available services and resources	
	Having a 'reason' and a plan	Doing something for others	<i>There was an outcome and the outcome was about the short movie. I think it was good we had an objective in mind, it wasn't just meeting to talk, we actually came with a kind of plan. (Participant)</i>
		Not a traditional 'support' group	
		Your experience is valued	
		Something to look forward to	<i>When it was on he was looking forward to it - he was off doing his thing. I thought it was good because he'd be sitting at home all day and then he'd have to make sure he woke up and go again. (Family member of participant)</i>
	Artistic expression	Opened things up, creating new understanding.	<i>it was enough to sit there and think about it and express yourself a different way (Participant)</i>
		A creative first for some	
		Challenging but worthwhile	
Strengths	The arts workers	Their encouragement	<i>I thought their interaction was really good and their enthusiasm and their comments. (participant)</i>
		Their skills	
	Meeting outside the AWCCC	Not associated with illness and treatment.	<i>Having another venue was perfect because it was a different atmosphere. Alan Walker is a good place but it's</i>
		Frogs Hollow	

			<i>there specific for a reason. (Participant)</i>
Challenges	Lack of structure	Evolving/Participant directed	<i>They sort of had it planned out but I think we railroaded that pretty well. (Participant)</i>
		Role clarity	
		Vague	
	Lack of control over end product	Extent of participant direction	<i>It would have been nice to actually be able to be involved in not just the talking and the writing side but the actual doing side, for me. (Participant)</i>
		Unsure of 'audience'	
	Complexity of creating animation	Time consuming	<i>It's a bit of one person job really, animation. It's very hard to do it as a group in general, so not the best group activity. (Arts worker)</i>
		Highly skilled	
	Arts-worker responsibility/ anxiety		<i>I feel a big emotional responsibility to do well by them and I can only bring my own interpretation to it and in some ways that feels a bit wrong too because it's their story and their voice (Arts worker)</i>
	Participant anxiety about art		<i>I think there was a little bit of resistance which is probably natural for people who've never written before or done writing projects or arts projects. I think they were a bit scared of the word 'art' (Arts worker)</i>
	Cost	Time	<i>I guess some parts were maybe initially unplanned, but if we were to do it again I'd put that into the budget (Arts-worker)</i>
		Money	
New Learning	Timing with cancer treatment	After treatment worked well	<i>I was trying to work at the same time, but when I was on treatment and I was working I was surviving and that was it. I'd get to the end of the</i>
	Balancing structure and flexibility	So participants know what they are getting into	

	Inviting people into the project worked	Would not have attended otherwise	<i>week and I was shattered, I'd have to be in bed by four o'clock or five o'clock. I couldn't have done an art project at the same time. (Participant)</i>
	Group size and composition	No more than 6. Mix of diagnosis and prognosis was beneficial.	
Ideas for the future	A book	Six to eight week projects, offered at regular intervals throughout the year.	<i>The participants are already talking about putting together an anthology; a book. So I'd definitely like to explore that further. (Heart project facilitator)</i>
	A film		
	Digital story books		

5.3 Results in Detail.

5.3.1 Benefits of the project

The benefits of the writing, animation and video project (also referred to as 'the film project'), were many. Participants experienced mutual support, learning, and creative expression, and a sense of meaning from contributing to something 'useful' for other people. Each of these benefits are explored in more detail here.

Support

All three participants advised that they were not really keen to access cancer support groups, but through taking part in this project came to value the support and encouragement they all offered each other. The following quotes from two participants demonstrate the value of support from people experiencing similar issues.

I haven't felt the need to see the psychologist since coming here. The psychologist tells you how to go through it. Here is different. (Project Participant)

It was good to be with others who understood, to be able to speak more frankly than with family - honestly and openly. (Project Participant)

Participants talked about the importance of being able to 'share the uncertainty' with others who knew what it was like. It was difficult for some participants to discuss these feeling with their close friends and family, as they were often trying to protect them from worry and concern. As one participant said:

Here [with the film project] you can let it all out and you feel a lot better for it. (Project Participant)

Sharing the desire for 'life to go on' was also a common understanding the three participants discussed with one another. The importance of living, even with a life-threatening illness, was something they could share with one another as the next quote shows.

The other really good thing that came out of it for me was understanding and compassion and the survivorship issues, which I hadn't really understood. One day a few months ago, it was only when I realised what survivorship was, it wasn't just about surviving treatment... It's about living. (Project Participant)

One of the arts workers summarizes the mutual support benefits of the project with the following quote.

I could see the massive benefits of those three participants just being able to talk and talk and talk and they just talked for like three hours in a row without stopping almost every single time, and they were really sad when they ended and they just wanted to keep going. (Arts worker)

Learning

Participants reported that the film project facilitated new learning about themselves and about the various resources available to them in the community. Each of the three participants express this learning about themselves in the following quotes that came from their conversation in the focus group.

It's actually been good to talk to you guys to find out that some of the things that I was going through everybody goes through, because I hadn't really talked to other cancer patients. (Project Participant)

It expanded my insight into the way I was doing things and the way I was thinking. (Project Participant)

This helped me to understand my own feelings and fears a lot more. (Project Participant)

Participants shared information about potentially useful resources that were available to them. The following quote demonstrates this.

We learned some of the practical stuff from each other, ie: mental health plan - no-one had suggested that to her, and now she's going on one, so are her kids and husband. (Project Participant)

Having a 'reason' and a 'plan'

The idea of creating something that would benefit other people was very important for all three participants. This provided a sense of purpose and a 'real reason' for getting together. Doing something for others was considered important, and two of the participants advised they were unlikely to have become involved if 'Heart' was pitched as a support group rather than being a project. These next comments make that very clear.

There was an outcome and the outcome was about the short movie as well, the animation. Yeah I think that was quite good the fact that we had an objective in mind, it wasn't just meeting to talk, we actually came with a plan kind of. (Project Participant)

It helped me as well, which I think was the ulterior motive. But I thought of it the other way, as what can I do for others. It's a little bit like a legacy for everything you've been through, I'm going to give it a positive outcome. (Project Participant)

I absolutely think it's been brilliant but I just don't think the product is the thing that is most beneficial, I really think it's been the process, and you kind of need a product to go through the process. (Arts worker)

Participants advised that they believed their own experiences were highly valued, by each other and by the arts workers. They talked about looking forward to attending the writing workshops sessions each week. The partner of one participant discussed how important this was in terms having something to plan for and look forward to.

When it was on he was looking forward to it - he was off doing his thing. And I thought it was good because he'd be sitting at home all day and then he'd have to make sure he woke up and go again. (Participants partner)

Artistic expression

The creative focus of the Heart project was very important for all participants. Each of them talked about uncovering different parts of themselves, and finding ways to express this. Writing 'opened things up', and created new understanding of past events, and ways to explore them. In the next few quotes, we can see the value of this new creativity and self-expression to all three participants.

But the best exercise I think we did, and what really I took home that night and thought 'wow', was when we had to describe what we thought if it [cancer] was an animal, what colour it would be, all those type of things. And I couldn't believe what I actually wrote down. So then on reflection when I got home, I'd never thought of it that way. Mine was a hyena and I would never have thought of it - I actually dug deep down and thought - why was it? So on self-reflection that actually helped me I guess move forward. (Project Participant)

It was good, even just to sit in there talking, it was enough to give you another avenue to go down type thing. And support groups are good but this was just a mind thing you could focus on type thing. (Project Participant)

It was part of the journey. And it was a journey to express yourself and I think it opened our eyes (Project Participant).

The Heart project was a creative 'first' for two participants who never thought of themselves as 'arty' before. The value of finding ways to 'break things down to a simpler concept', and 'put your stories into layman's terms' meant that for some participants, expressing themselves became easier. Participants noted that it 'stops you from bottling it up', and acknowledged that it was 'better to let it all out'. The power of finding a new outlet for expression is clear in the next two quotes.

I only went to Grade 10 in high school and I don't consider myself a writer but it was like a big vomit thing. Because a lot of the times you don't get to sit down and talk about how you feel and whatever is really hard with someone that doesn't know what it's like and you border on thinking 'oh god they're whinging again' or 'it can't be that bad' or 'how peculiar to have those thoughts'. (Project Participant)

I never went to those sessions with him. That was his thing and his way of dealing with it at his stage of life. It was so funny when he came home and said he had writing homework, I got a good laugh that afternoon thinking him? Write? I can't even get more than three words on a text message let alone writing for homework. And I'm thinking 'oh dear this is going to be good!' (Participants partner)

The processes involved in reflecting, discussing, thinking and writing were not easy. Participants each talked about the way in which the writing task were challenging but ultimately worthwhile. We see this in the following quotes taken from a focus group conversation between the three participants.

It did facilitate some good self-reflection I have to say.

Yeah, and the writing, as much as I'm not keen on writing for pleasure it was a good vehicle to do it.

Yeah it sort of opened up with trying to adapt the cancer to an animal type thing.

Or a colour or an emotion.

Yeah and it doesn't sound that hard but you sit there and you think about it.

Some days it was very hard.

But then you get it out on a piece of paper and you think 'oh, okay'.

A staff member from the AWCCC also expressed the view that participants benefitted 'psychologically' from the opportunity to express themselves creatively, as we can see clearly from the next quote.

The film had such a positive effect for the patients involved, more than I would have ever thought. The psychological benefit in terms of expressing their cancer journey in different artistic forms, and the support and friendships they made within the group I feel had a direct individual patient benefit. (AWCCC staff)

5.3.2 Strengths

When asked about the strengths of the film project, the project participants all pointed to the arts-workers. The development of strong relationships between workers and participants was a cornerstone of the project. The venue, Frogs Hollow in Darwin city, was also considered a strength, primarily because it was not the AWCCC. These two themes are explored further here.

The arts-workers

The arts workers were considered to be skilled, patient and encouraging by the project participants. Participants' feelings about this encouragement, and its importance in terms of facilitating participation, can be clearly seen in the following quote.

I found Mary Anne and Huni the way that they interacted with us, their compassion and the way they told us all the time 'what you've been through you're unbelievable, you're this, you're that', their stories of encouragement. And Mary Anne about her own journey a couple of times and the girls about theirs, I thought their interaction was really good and their enthusiasm and their comments. (Project Participant)

The artistic skill of both arts workers, as well as their listening skills, were greatly admired and appreciated by the participants. The next snippet of a focus group conversation between the three project participants demonstrates how these skills worked together at each workshop.

It was good to sit down with Mary Anne and Huni and think about things in a different perspective.

I felt for Mary Anne because she's such a natural writer and we're like no, no!

But I think she just realised that we weren't natural writers and she just let it be type thing.

Went with it.

Yeah, sort of pushed us in a little direction.

They were very good at keeping us under control and bringing us back.

Keeping the focus.

The arts workers also discussed their understanding of their role in creating this supportive environment, of being a listener, as well as a creative facilitator.

I think the strengths of the projects are really just the human contact of having all of us together and I think Mary Anne and I in the workshops were just listening, really active listening, just listening for two to three hours and we barely talked and we didn't need to. I think it was really good for them to be able to talk, not just with each other but also with us, as strangers to begin with but not as doctors and not as psychologists, you know what I mean? We would just be weird artists who were listening and were interested and I think maybe that opened up a different avenue of how to talk about things. (Arts worker)

Meeting outside AWCCC

It was important for participants that the project was not located at the AWCCC. There were simply too many 'treatment' associations linked to the centre, so being in a really different place meant the focus was on arts and creativity, rather than on illness or treatment. As one participant noted:

These sessions are not about your treatment, but about your journey. (Project Participant)

An AWCCC staff member also believed that holding activities outside of AWCCC was important for similar reasons. The venue used for the script writing part of the film project was considered to be a 'beautiful old building', and as one participant pointed out

It was perfect because it was a different atmosphere. (Project participant)

5.3.3 Challenges

There were a number of challenges highlighted by all evaluation participants. Most centred on the 'pilot' nature of the Heart project, and the commitment to being participant driven, both of which resulted in a perceived lack of program structure. The desire for a more clearly articulated vision and/or framework for the film project was expressed by almost everyone. The issues are teased out in some detail here.

Lack of Structure

The film project participants were invited to join the project by the AWCCC Clinical Nurse Manager. From the outset it was not really certain what participants were being invited to do, other than participate in something that would involve writing, animation and creating something that would benefit others who embark on similar cancer treatment journeys. Some participants wanted a clearer overview at the start. Everyone was unsure of the scope, the aim and '*what it is all about*'. The following focus group conversation between project participants expresses these ideas, but also demonstrates that the participants felt they could control the process too.

It was vague, no structure.

Yeah at the start of it I think Mary Anne and them they sort of had something already in mind.

They had a plan?

They sort of had it planned out but I think we railroaded that pretty well!

While the participants thought the arts workers might have had a set plan, the arts workers had been prepared for a more participant-led experience. They too found elements of the evolving and 'organic' project frustrating, but also rewarding as we can see from the next quotes.

I found myself a bit frustrated with the process at first because of the organic nature of it. I tend to run workshops from a very structured perspective, with a clear map for the session, goals articulated, handouts etc. from the Heart brief, these workshops tended to lend themselves to a more organic process, so for me it was a question of balancing my preference for structure with this more organic brief. I'm still not sure if I got that balance right. (Arts worker)

It was always to be participant directed, and I think the participant directed approach has its pluses and negatives. I think the tricky bit is to create an art project with people who have never really done anything in the arts before, so for me maybe that leap was, in my observation, quite a big one for all of us. But the excellent, excellent thing about seeing, and attending all those workshops and doing it with [other arts worker], was just getting to know everyone's stories and they're incredible stories. (Arts worker)

The arts workers also pointed out that there were some issues with fully understanding their own roles within the project at various times. One arts worker explains the problem from her viewpoint.

I think another thing is maybe to clarify roles really well at the beginning.I think also we got a bit confused in the end there. I thought one of us was sort of writing it and the other was animating it, but my colleague didn't think that, she thought she was just writing, running the workshops and that's where we both looked at each other and went "oh, oh I thought you were" "no I thought you were, oh"! (Arts worker)

This balancing between having a clear structure and making room for flexibility and participant-direction was a key challenge for the Heart program facilitator. As the next quote clearly highlights, being open and flexible to the needs of all stakeholders meant some aspects of the planned project changed significantly during its delivery.

Some things have changed a lot and staff have come back and said, "Look, you're going to do this but instead can you do that?" So for instance, with the film project, the film project was supposed to be with young people and when AWCCC staff spoke to young people, they were either too ill because their treatment is really full-on or they weren't around enough. So she came back to saying, "Well how about this other group," or "Can we just open it up?" It's like, "Absolutely we can." So that's the best example of something that's really changed quite radically, certainly as far as the target group goes. We could have been very closed minded but no, I don't think I would do anything differently. (Heart Project Facilitator)

Lack of control over end product

While aspects of the film project were participant-led, the participants expressed a desire to have more say in the end product. At the time of the focus group, participants had completed the writing workshops but were uncertain as to what the final film would look like and who the audience would be. This was clarified very soon after and the resulting film contained elements of each participant's own story and advice, as well as animation focused on their explorations of cancer as an animal. In terms of future projects, participants provided the following advice.

The way we were talking it would be nice if they were going to do this again if people could actually have more input into the artistic side of it. I do this kind of stuff with my kids all the time, you put stop motion videos together, they're not going to be as classy as some of the others, and you put in your own images and stuff. And it would have been good in a way, what you can do with an iPad these days, to actually do some of that production stuff and put the images in as you want them. (Patient Participant)

One of the arts workers also suggested that there might be better ways to involve participants more in the making of the film and/or animation aspect. By being involved in all aspects participants could have more responsibility for the content and intended audience. The next quote highlights this point, and also suggests (as the previously quoted participant did) that stop-motion animation could be a way forward.

It's also good in future to think about them making their own product so that really they take responsibility for the tone and the expression as well, rather than an artist doing that..... You know you could do stop motion, you could do model

making, but again it takes quite a lot of time because it's like one movement is one frame, you know twenty-five scenes a second so it's really, really time consuming (Arts worker)

Not knowing who 'the audience' for the end product is, was a problem for some participants. The following questions were raised: Is it medical advice, or is it for the benefit of the participants? Who will see it and what is it for? Some felt that it was not until the film was totally finished that they really knew what it was going to be.

Animation is a complex medium

The arts worker responsible for the animation felt that animation may not be a good medium to work with for a truly collaborative project. While people were generally happy with the end result, the process took much more time than was planned, and there was not budget to cover this. She pointed out that animation is often solo, time consuming and can be very costly. It is difficult to make changes that participants may desire, as each change takes many hours of work. The arts worker made the following important comment.

It's a bit of one person job really, animation. It's very hard to do it as a group in general, so not the best group activity.....It was a matter of trying to find something that was realistic for the time and money, but still honoring what their stories were. I think we found that balance, I hope we did. (Arts worker)

Arts workers anxiety

Closely related to the above comments was the anxiety or concern that arts workers felt at various points in the process. They were very aware that they were working with people who were facing a major life experience, and wanted to be respectful of that.

I also felt a little bit anxious at the end, that I had no idea what I was going to make, and that the journey's just so huge and there was so much to cover and it's quite a big responsibility to try and encapture all of that in a very small film or animation.... I feel a big emotional responsibility to do well by them and I can only bring my own interpretation to it and in some ways that feels a bit wrong too because it's their story and their voice. (Arts worker)

Participants fear of 'art'

Participants also had their own concerns and fears about 'art' and whether they could 'do it' or not. While they reported feeling nervous about some activities, they mostly got over their fears quite quickly; however it could be a struggle for arts workers attempting to engage people at the outset.

I think there was a little bit of resistance which is probably natural for people who've never written before or done writing projects or arts projects. I think they were a bit scared of the word 'art'. Over time, I think it was just a trust thing, to trust in themselves that they could do it. Maybe a bit of fear of what it meant to explore such deeply emotional processes that they were going through, but they always said they got a lot out of it so I think the fear was just probably a natural nervousness that they'd do the wrong thing or that they weren't writers or that they didn't know how to write. (Arts worker)

At times, reluctance to fully engage in the writing work meant arts workers needed to be flexible in their approaches. Time was sometimes spent 'managing' the different personality types and their responses to creative processes. This could be difficult for the arts workers as they attempted to manage group dynamics and an artistic endeavor. The following comment expresses this concern.

We also had some who were really reluctant to write... (Perhaps out of fear), and much of what I had prepared were writing exercises..... these moments at times became about people management at the expense of depth of content. (Arts worker)

Financial/Time costs for artists

One arts worker pointed out that because the film project was quite unstructured and flexible, they were not really able to adequately estimate the amount of time needed, and the costs involved. While they were happy to 'go with the flow' so that the pilot project could be completed, they advised that future work would need more budgeting resources to cover the cost of the time spent on it by arts workers.

5.3.4 New Learning

In this section, the learning associated with the pilot film project has been gathered together for future reference. The evaluation participants learned that; such a project requires a little more structure, it is important to invite potential participants to be part of the project, group composition is critical, as is the timing of participation in relation to cancer treatment schedules.

The importance of balancing structure with flexibility

Following on from the comments in the 'challenges' section, a key learning is to provide participants and arts workers with a little more structure. While acknowledging that flexibility is essential, and it is difficult to get the balance right, each participant believed that some clearer understanding of what they were getting involved in would be useful for future versions of the project. The following comments provide some ideas of what people would like.

'This is how long'. And 'this is what you'll be expected to do'. Because structure is very important for making people feel safe so you can say 'okay yep I can do that that's easy'.... For the people that aren't always going to seek out support groups, they need to know they are doing this for somebody else - then you may get some of those people who are less likely to seek support in other ways. (Project Participant)

It doesn't have to be over-structured just some basic guidelines...Just the basic plan that's all you need. (Project participant)

People need to be invited into the group – don't wait for them to ask.

Each of the participants pointed out that they were very unlikely to have responded to an advertisement for participants in the film project, yet when they were approached by the AWCCC staff, they felt it was something suitable for them, that they wished to try. They also liked the diversity of group members, and felt that being 'handpicked' for the project was important. The following two participant comments highlight these points.

I think people should be asked to join in. (Project Participant)

I think it is good to be asked, and to have different types of cancer, because there seems to be a bit of disparity in support available for different cancers. I think the fact that you ask people means you may be able to pick up those people who are less likely to join things, or people who might benefit but not know it. (Project Participant)

Group Size & Composition

The size of the group is important in terms of participants' abilities to support each other and share. Participants recommended that groups have no more than six participants. The following focus group conversation snippet demonstrates participants' views on this.

Probably five to six or something. Six would probably be the maximum you'd have in something like that. (Project Participant)

You get a lot of emotions and a lot of stuff comes out of it, I think if you had too many people they might be a bit more reserved. (Project Participant).

The question of whether to mix together people who are recovering and/or in remission with people who are unlikely to be cured was raised in the focus groups. Participants thought that it would be fine, and the following focus group quote demonstrates that mixed group composition can provide a sense of hope and emphasize the importance of living.

[It would be okay to have that mix], because one thing we got out of it is, we all think it [cancer] might come back.

Yeah, might get us in the end.

Well I mean I knew that I'm not going to get better. I'm just going to keep going the way I am or whatever, but I didn't think that at all. In fact to me it gave me sort of like...

Gave me ambition to keep living.

I found the relationships and listening to both about how it affected family and how they dealt with it and all that stuff made me reflect on how I was treating my family and how to deal with it. So it was all about what you're going for and living for at the moment.

Timing with cancer treatment

The timing of the project is important, and participants felt it would be better to run a project like this one after cancer treatment, rather than during it. The reasons for this are explained in the participants own words.

When I was on treatment and I was working, I was surviving and that was it. I'd get to the end of the week and I was shattered, I'd have to be in bed by four o'clock or five o'clock; I got to the stage where I could barely drive myself home because I was so exhausted. So adding something else [like the film project] would have been another thing and I may not have coped as well. (Project Participant)

An AWCCC staff member advised that timing was critical, and was also one of the main reasons why such a project should be located outside of the AWCCC, preferably when the intensive treatment phase is complete. The following comment explains way.

I found it difficult to get a lot of patients involved. This is because of many reasons, new cancer diagnosis, feeling overwhelmed by treatment, feeling unwell. I think there are a lot of patients who are emotionally and physically very acute whilst undergoing treatment. And sometimes they may feel an added pressure by even being asked to participate. (AWCCC Staff)

5.3.5 Ideas for the future

The ideas discussed for future projects included a book, another film, and digital story books. Each of these is presented here.

A Book

Participants felt that a book containing people's stories about their cancer journeys through the AWCCC, and that was available for people to read in the Chemotherapy suite would be a very useful and helpful resource. The following ideas were articulated.

One of the arts workers had a book and it was on cancer, like short stories - and we brought it up with them [arts workers], if we could get something like that next time and have it at the Alan Walker Centre so people can read it and go 'oh okay it's not only just me, it happens probably to everyone'. (Project Participant)

One thing that they were quite passionate about, and that could be a good idea is that maybe rather than make an animation or a video, is an anthology or actually have them write things down and collect those writings and edit them, which we talked about as a group. I think it would be more time efficient, money efficient and you wouldn't actually need a studio space or materials or six months to create something. (Arts worker)

Film (documentary)

The idea of a different kind of film idea was raised by one participant. It was thought a documentary about the group itself would be a useful and informative project, that could go hand in hand with the creation of a book or similar project. The next quote from an arts worker provides an idea of how and why.

The other thing is a documentary, often I thought when they were talking "oh wow wish I had the camera on now" because it's really fresh when they're talking during the workshops. Whereas afterwards things aren't as fresh as well, you can't really capture those things again on film and I thought the group conversations were so fascinating and so interesting that if you did take a camera to those and cut more of a bit of a doco together. (Arts worker)

Digital Story Books

The suggestion of developing digital story books with participants was also raised. The idea is that people can make it into whatever they would like. It could be a story of a person's journey, thoughts or advice and support for others experiencing cancer, or possibly a legacy for family members and friends. The idea is expressed in the next quote.

The product could be a digital story, they could take pictures, they could write one of their stories, they could combine all sorts of things from different workshops into their own digital story or something like that so that it's their product. (Arts Worker).

5.4 Summarizing the Film Project

The film project took a short while to 'find its feet'. The intended participant group (young people) did not eventuate, nor did the original full animation idea. Ultimately the project ended up with three very keen and engaged adult participants, who together with two committed arts workers, created a meaningful film. Participants did not consider themselves to be 'arty' and were at times difficult to keep 'on track' with the project tasks, but each eventually felt creative and productive in terms of developing up the final film. The key benefits of the film project were in the 'accidental support' each participant gained. This support could not have occurred without having the 'excuse' of the film project to bring people together and allow them to open up creatively and emotionally. Every stakeholder in this evaluation overwhelmingly agreed that this was a useful and worthwhile project that they would like to see happen again.

6. Evaluation Summary & Conclusion

The primary objectives of the 'Heart' project were to further enhance the holistic approach to cancer care delivery and improve the patient experience. The aims of the Heart project *evaluation* were to:

1. Understand the benefits, challenges, strengths and weaknesses of the 'Heart' arts-in-health program, from the perspective of program participants and their families, AWCCC staff, and arts-workers involved in the program.
2. Explore the extent to which program objectives have been met.

The evaluation has demonstrated that the film project formed an important part of a holistic approach to cancer care. Many of the emotional, social, creative and support needs of the three participants were partially met via the Heart Project. It was clearly beneficial to the three AWCCC patients who participated in it. The AWCCC based activities had a range of different outcomes; however there is general agreement that having arts activity in the centre helped to enliven the space for patients and staff. The strengths and weakness of the two different elements of the Heart project are again summarized here.

Activities based in the AWCCCC

- The **benefits** of the AWCCC based activities included positive distraction from cancer treatment for patients and staff, and an increased feeling of wellbeing in project participants immediately after the arts activity.
- The **strengths** of the project were the arts workers, the supportive context and the artistic products created.
- The **challenges** included engaging patient participants, determining the best structure and timing for the activities, and understanding what kinds of art worked best in the environment.
- The pilot project facilitated **new learning** about the importance of flexibility in project delivery, and the equal importance of process (that included conversation and observation of art creation) and product in the art making,

The film project

- The major **benefits** for participants in the film project included mutual support, new learning, having a 'reason' and a 'plan', and being able to creatively express themselves.
- **Strengths** of the film project were the arts works and locating the activities outside of the AWCCC.
- **Challenges** were the initial lack of project structure, lack of participant control over the final product, arts worker and participant anxieties, the complexity of animation as a story telling medium, and time and resources required.
- Much was **learned** about the size and composition of the group (no more than six people, scheduled after treatment and with a mixture of people with different diagnosis and prognosis). Balancing structure and flexibility, and ensuring that potential participants are personally invited to attend by their health care or support providers were also key learnings.

7. Recommendations

The Heart Project has provided clear benefits to participants, arts-workers and the AWCCC staff involved in the project. While there were also challenges, these were outweighed by the program strengths, and the rich outcomes documented in this evaluation.

As a pilot project Heart has been successful in exploring 'what works' in two different contexts. There is good potential for the growth of the Heart Project through the learning that occurred throughout the project, and via the integration of ideas generated during the reflective evaluation process. For these reasons the Heart Project should be continued and extended so that benefits can be shared with a wider group of participants.

Recommendations for the continuing evolution of the Heart Project include:

Artist in residence at the AWCCC

- Given that art activities involving too much 'hands on' action were problematic in the chemotherapy and radiotherapy treatment context, the idea of an artist in residence is a useful one to explore.
- The artist in residence could create artwork within the AWCCC so that patients could observe the process and the products. The artists would also need to be a very 'personable' type who would happily engage patients in conversation about the work, providing much needed diversion.
- Depending on resources, the artists could also run specific, low 'hands on' action, workshops within the centre at regular times, for family and patients.
- The artists could also liaise with AWCCC social workers and/or psychologists to assist with conversations and suggestions of other diversional activities.
- The artist in residence program could act as a conduit or 'conversation starter' providing links or invitations to community based arts activities. Patients could take up these invitations when their treatment is complete or when they feel ready.

An arts program based in the community

- An arts program one afternoon/evening per week at a location outside of the AWCCC.

- This program would be open to people living with or recovering from cancer.
- They could come together and work on specific arts projects facilitated by a project worker. Suggestions from participants included 6 – 8 session ‘blocks’ of each of the following art forms
 - Creative writing towards the development of a book or anthology of stories from the AWCCC
 - Short film (documentary style)
 - Digital story books (the content could be autobiographical, fiction, cancer-experience related, wellbeing and health advice to others, whatever the person wished)

It is hoped this evaluation can contribute to arts, community and health services understanding of the usefulness and effectiveness of arts activities within the cancer journey.

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Appendix A

Project Participant interview questions.

1. What 'Heart' program activities did you participate in?
2. What did you think about the activities?
 - a. What worked well for you and why?
 - b. What wasn't that good and why?
 - c. Is there anything you would change or like to see in the program?
3. Do you have a particular anecdote or story you would like to share about the program?
4. Did participation in 'Heart' program activities bring about any non-arts related outcomes for you? (e.g. friendships, other interests)
5. Would you recommend it to others? Why/why not?

Arts Worker interview questions

1. What activities did you facilitate in your role as a 'Heart' program arts worker?
2. What was your experience of the work?
 - a. Was it easy, fun, difficult, challenging – why?
 - b. Was the context supportive to your work (staff, resources, time etc.)?
3. What benefits do you think the patients received from participating?
4. What did you learn from the work?
5. What might you do differently next time?
6. What do other arts workers in similar programs need to know?