

Palliative Care Australia Conference; Melbourne 2015  
**Volunteers Day**

# **Evaluation Project**

## **Building Community Capacity with Volunteers**

Andrea Grindrod, Bruce Rumbold, Wendy Dagher, Palliative Care Unit,  
Department of Public Health, La Trobe University

[a.grindrod@latrobe.edu.au](mailto:a.grindrod@latrobe.edu.au)

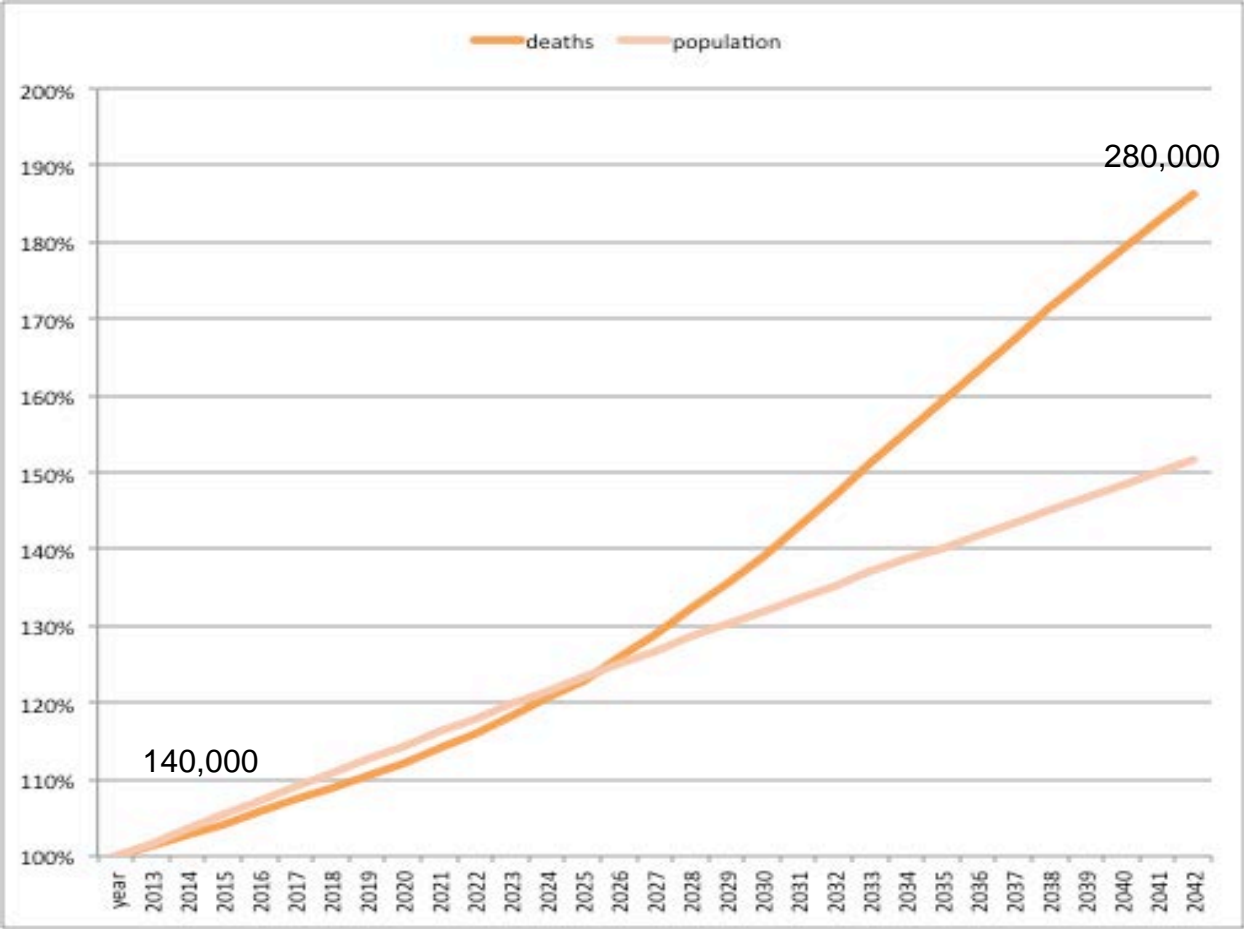
# This session...

- ❖ Individual and group activity
- ❖ Look at the 3 community capacity building projects with volunteers across the state
- ❖ Briefly outline the evaluation design
- ❖ Discuss the results

Why are we interested in building community capacity and resilience in the Victorian community on issues related to death, dying, loss and bereavement?

*What is working now (?) is unlikely to work in the future...*

# Demographic increase in dying

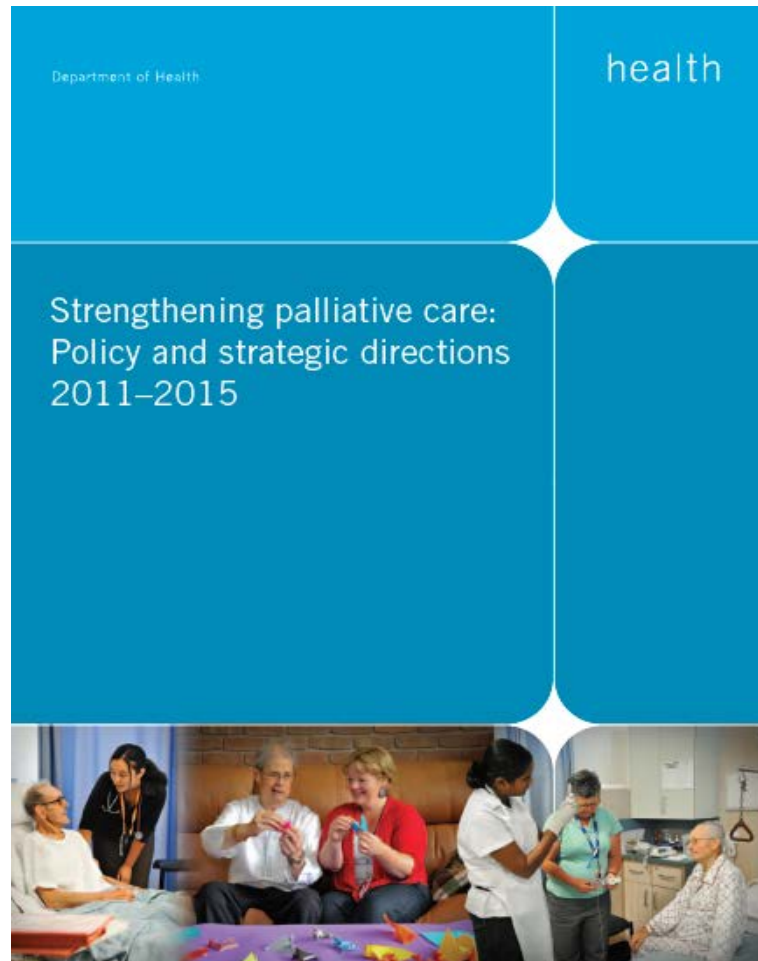


Source ABS 2012

# Activity...

- ❖ Take 5 minutes to quietly jot down your reflections on the 3 questions
- ❖ Take 10 minutes to share your reflections with the group at your table
  - *Nominate 1 person to take notes of the themes in the group discussion*
- ❖ Share the main themes from your discussion with the broader group

# Community Capacity Building: Evaluation Project



Evaluate the effectiveness of, and develop an evidence base for, community capacity building activities

Victorians are better able to support people with life-threatening illness, and their carers

**Department of Health and Human Services**  
**Strengthening palliative care: Policy and strategic directions 2011-15**

**Strategic Direction 7:** Ensuring support from communities

**Action:** Strategies to enhance opportunities for palliative care service volunteers to engage with their communities

**Impact:** Victorians are better able to support people with a life-threatening illness and their carers

**Palliative Care Victoria  
Project Management**  
2013 - 2015

**Calvary Health Care Bethlehem**  
The Schools Project

**Gippsland Lakes Community Health &  
Gippsland Region Palliative Care Consortium**  
Making the Last Chapter Reflect the Whole Book

**Olivia Newton John Cancer Wellness Centre**  
Pondering Mortality

**La Trobe University  
Palliative Care Unit**

**Process, Outcome Evaluation  
2013-15**

**Impact Evaluation  
2014 - 2017**

Palliative Care Victoria (PCV) Project Steering Group Committee

**LTUPCU EVALUATION**  
Process & Outcome Evaluation  
Impact Evaluation

Olivia Newton John  
Cancer Wellness Centre  
**THE STORYTELLING PROJECT**  
(Legacy)

Calvary Health Care Bethlehem  
**SCHOOL PROJECT**  
(Death Education)

Gippsland Lakes Community Health &  
Gippsland Region Palliative Care Consortium  
**LIFE REVIEW PROJECT**  
(Community & Value Based ACP)

**EVALUATION MODEL**

**1) Process & Outcome Evaluation: (Quantitative & Qualitative)**

Process & Outcome data (what, how, who, when & why) will be collected by online surveys to the key project participants at the end of Phase 1 & at the end of Phase 2. This part of the evaluation is designed to capture processes related to project implementation.

This important information will guide external organisations that are interested in replicating the projects. We want to know what worked well, and what didn't work well when implementing the project.

**2) Impact Evaluation: (Qualitative)**

Impact evaluation data (what impact or change did the project have on all participants) will be collected using the Most Significant Change (MSC) Technique (UK).

MSC is a participatory & inclusive evaluation approach that offers opportunity for all project participants to contribute equally to the outcomes and impact of their work.

This approach specifically includes project monitoring (useful for new & developmental projects) and is effective for capturing impact data throughout the project, as opposed to at the end of the project in traditional impact evaluations. Unanticipated or unexpected outcomes are also catered for in this approach.

**PHASE 1: VOLUNTEER CAPACITY BUILDING – EVALUATION QUESTIONS**

1a) What capacity is being built in the volunteers to prepare them to deliver the community program & how is this capacity being built?  
1b) What are the most significant changes for the volunteers as a result of participating in this program?

**Volunteer Model**  
Recruitment  
Training  
Support  
Retention  
Sustainability

**Volunteer Capacity**  
Facilitation of Arts in Health Skills

**RESOURCE**

Development of an Audio Visual Resource of storytelling & legacy through a public arts installations

**Volunteer Model**  
Recruitment  
Training  
Support  
Retention  
Sustainability

**Volunteer Capacity**  
Group facilitation & public speaking skills

**RESOURCE**

Audio Visual Resource developed during a public event of student artwork & storytelling created through project implementation

**Volunteer Model**  
Recruitment  
Training  
Support  
Retention  
Sustainability

**Volunteer Capacity**  
Organisational Community Capacity Building through local Service Clubs

**RESOURCE**

Development of an Audio Visual Resource that supports life review & values based ACP conversations in the community

**PHASE 2: COMMUNITY CAPACITY BUILDING – EVALUATION QUESTIONS**

2a) How & when were the community sessions facilitated by the trained volunteers utilising the resource?  
2b) What are the most significant changes reported by the volunteers & participants attending volunteer led community sessions?

**Community Capacity Building**  
Delivery of volunteer facilitated community sessions in hospital & community settings

**Target group** – patients, families, carers & community members

**Community Capacity Building**  
Delivery of volunteer facilitated community sessions to schools & other community settings

**Target group** - Young people

**Community Capacity Building**  
Delivery of volunteer facilitated community sessions in local Service Clubs (Rotary, Lions)

**Target group** – Ageing population

**IMPACT EVALUATION (PCU & PhD Candidate) 2014 – 2016**

*Community Capacity: Individual & community resilience in relation to dying, death, loss & bereavement*



# Evaluation Framework *(for programs)*

PROCESS EVALUATION: VOLUNTEER & COMMUNITY CAPACITY BUILDING		
	Volunteer Model	Project description (Process Evaluation)
Phase 1	1 Recruitment	Approaches and Key Learnings
	2 Training	Methods and Content
	3 Support	Required and Type
	4 Retention	Strategies and Challenges
Phase 2	5 Program Sustainability	Planning, Strategies and Challenges
	Resource Development	Process for the development of the resource
	Community Partnerships	Building partnerships outside the health sector
	Promotion and Marketing	Promoting the project in community
	Community Session: Pilot	Session evaluation results
	<i>Project Challenges</i>	<i>What not to do: learning curves</i>
	<i>Advice to Others</i>	<i>What to consider: Key learnings</i>
	<b>Outcome Evaluation</b>	<b>What are the immediate outcomes of this project?</b>
	<b>Helpful Hints: Top 10!</b>	<b>What are the key learnings from the project teams?</b>

# Objectives of the Evaluation 2013-2015

Our evaluation involved:

1. Examining and documenting the processes and strategies used in delivering community capacity building projects
2. Analysing and documenting project outcomes
3. **Identifying key enablers and barriers to implementing this learning**

# Calvary Health Care Bethlehem

## *'The Schools Project'*

- produced a death education program designed for school settings
- began with an experiential immersion program in palliative care for Year 10 students of Sacred Hearts Girls College (SHGC) Oakleigh (and training volunteers)
- the immersion program supplied material for developing a DVD resource
- the resource is incorporated in a classroom session on death, dying loss and bereavement, delivered by the trained volunteers of the project



















K



Always know  
when death  
is near



that there is  
nothing you  
need to fear



K



BRIGHTON



## Life and death moments inspire artwork

BRIGHTON Library is hosting a collaborative art project about palliative care until the end of the month. The exhibition, called *Reflections on Palliative Care* is a series of artworks by Year 10 students from Oakleigh's Sacred Heart Girl's College about their visits to Calvary Health Care Bethlehem. Meghna is pictured with her work *Everlasting Existence*.

Picture: CHRIS EASTMAN



# Snapshot Process Evaluation Results

PROCESS EVALUATION: VOLUNTEER & COMMUNITY CAPACITY BUILDING		
	Volunteer Model	Project description (Process Evaluation)
Phase 1	1 Recruitment	Approaches and Key Learnings
	2 Training	Methods and Content
	3 Support	Required and Type
	4 Retention	Strategies and Challenges
Phase 2	5 Program Sustainability	Planning, Strategies and Challenges
	Resource Development	Process for the development of the resource
	Community Partnerships	Building partnerships outside the health sector
	Promotion and Marketing	Promoting the project in community
	Community Session: Pilot	Session evaluation results
	<i>Project Challenges</i>	<i>What not to do: learning curves</i>
	<i>Advice to Others</i>	<i>What to consider: Key learnings</i>
	<b>Outcome Evaluation</b>	<b>What are the immediate outcomes of this project?</b>
	<b>Helpful Hints: Top 10!</b>	<b>What are the key learnings from the project teams?</b>

# Gippsland Lakes Community Health

## *'Making the Last Chapter Reflect the Whole Book'*

- sought volunteer and community engagement from the outset to develop, then implement, the program
- produced a values-based, pre-Advance Care Planning program to engage with the ageing community in the local area
- created a DVD featuring local people sharing their end of life plans
- an interactive community session run by trained volunteers explores how personal values for living might inform end of life decision making
- **DVD Viewing**

# Snapshot Process Evaluation Results

PROCESS EVALUATION: VOLUNTEER & COMMUNITY CAPACITY BUILDING		
	Volunteer Model	Project description (Process Evaluation)
Phase 1	1 Recruitment	Approaches and Key Learnings
	2 Training	Methods and Content
	3 Support	Required and Type
	4 Retention	Strategies and Challenges
Phase 2	5 Program Sustainability	Planning, Strategies and Challenges
	Resource Development	Process for the development of the resource
	Community Partnerships	Building partnerships outside the health sector
	Promotion and Marketing	Promoting the project in community
	Community Session: Pilot	Session evaluation results
	<i>Project Challenges</i>	<i>What not to do: learning curves</i>
	<i>Advice to Others</i>	<i>What to consider: Key learnings</i>
	<b>Outcome Evaluation</b>	<b>What are the immediate outcomes of this project?</b>
	<b>Helpful Hints: Top 10!</b>	<b>What are the key learnings from the project teams?</b>

# Olivia Newton John Cancer Wellness Centre

## *'Pondering Mortality'*

- uses creative arts to encourage participants to ponder their mortality and share their insights with significant others
- developed a DVD from a Dying to Know Day event held at ONJCWC
- The DVD presents participants' stories of dying and death, of regrets and loss
- In the accompanying education session art materials are supplied to encourage participants to reflect upon their mortality, to share these reflections with the group using the arts representation each participant has produced, and subsequently use the representations to share with other members of their social network



# Snapshot Process Evaluation Results

PROCESS EVALUATION: VOLUNTEER & COMMUNITY CAPACITY BUILDING		
	Volunteer Model	Project description (Process Evaluation)
Phase 1	1 Recruitment	Approaches and Key Learnings
	2 Training	Methods and Content
	3 Support	Required and Type
	4 Retention	Strategies and Challenges
Phase 2	5 Program Sustainability	Planning, Strategies and Challenges
	Resource Development	Process for the development of the resource
	Community Partnerships	Building partnerships outside the health sector
	Promotion and Marketing	Promoting the project in community
	Community Session: Pilot	Session evaluation results
	<i>Project Challenges</i>	<i>What not to do: learning curves</i>
	<i>Advice to Others</i>	<i>What to consider: Key learnings</i>
	<b>Outcome Evaluation</b>	<b>What are the immediate outcomes of this project?</b>
	<b>Helpful Hints: Top 10!</b>	<b>What are the key learnings from the project teams?</b>

# OUTCOME EVALUATION

## PROCESS EVALUATION: VOLUNTEER & COMMUNITY CAPACITY BUILDING

Volunteer Model		Project description (Process Evaluation)
Phase 1	1 Recruitment	Approaches and Key Learnings
	2 Training	Methods and Content
	3 Support	Required and Type
	4 Retention	Strategies and Challenges
Phase 2	5 Program Sustainability	Planning, Strategies and Challenges
	Resource Development	Process for the development of the resource
	Community Partnerships	Building partnerships outside the health sector
	Promotion and Marketing	Promoting the project in community
	Community Session: Pilot	Session evaluation results
	<i>Project Challenges</i>	<i>What not to do: learning curves</i>
	<i>Advice to Others</i>	<i>What to consider: Key learnings</i>
<b>Outcome Evaluation</b>		<b>What are the immediate outcomes of this project?</b>
<b>Helpful Hints: Top 10!</b>		<b>What are the key learnings from the project teams?</b>

# Most Significant Change (MSC) Technique

- ❖ Routine data collection methods for process evaluation
- ❖ A story-telling technique for evaluation
- ✓ everyone can tell stories about events they think were important
- ✓ it is a good means of identifying unexpected changes
- ✓ it requires no special professional skills; easy to communicate across cultures
- ✓ it can be used to monitor and evaluate bottom-up initiatives that don't have predefined outcomes against which to evaluate
- ✓ focuses on **learning** rather than just accountability

# MSC Question...

The core of the MSC process is a question along the lines of:

*'Looking back over the last (insert set timeframe), what do you think was the most significant change in [particular domain of change] for project participants?'*

## OUTCOME EVALUATION RESULTS

# **‘The Schools Project’** *Calvary Health Care Bethlehem*

Three main themes were identified from the Most Significant Change (MSC) stories:

1. Personal Growth and Learning
  - a. Sub-theme: Understanding of Death
  - b. Sub-theme: Appreciation of Life
2. Confidence to Talk about Death
3. Connections with Others

*“I learnt more about myself as a person through the sessions, have learnt how to deal and recognise my own emotions. I have a change of perspective in how I view life.” (SHGC, Student)*

*...I was able to have a conversation about what my mum wanted at her funeral. She wanted an Elton John song to be played. I am glad that I can now openly talk about death, I can fulfil my mum’s wishes. I am a lot more comfortable about talking about death. (SHGC, Student)*

*...How receptive young people actually are to the concepts of death and dying. I thought there would be much more apprehension toward the topic, however young people are more curious than fearful and this is something that should be expanded upon. (CHCB Volunteer)*

*When I applied for the Bethlehem project I wanted to challenge myself. Talking to patients, doctors and being part of the Bethlehem project has made me trust and be open to new things... I think particularly today on 28/11/14 when I had a chat with Mr. D I felt I overcame something. I am a very shy and awkward person. I had some difficulties in life. My family experience difficulties when my father suddenly became ill. This was tough as my mother had to raise the family. I had really never mentioned this to anyone ...*

*It is still hard dealing with it now. However, the Bethlehem project has made me into a stronger person. Changed me into a whole person as I experience an empowering journey.  
(SHGC, Student)*



## ‘SEEMINGLY SO’

*Once when we were going around Bethlehem Palliative Care hospital, we went to speak with a physiotherapist about her job. She had a cane – which I thought was ironic if she had to use it – and she took the cane with her into the room with all the physio equipment. Once we were there I didn’t think twice about that cane. The woman then began to tell us a story about a man who had walked into Bethlehem with the cane but it wasn’t very effective because the bottom didn’t have a rubber stopper. She then proceeds to tell us how she searched everywhere for a stopper so the man could walk with his cane, because he had refused the hospital issued ones, but by the time she found one his health had deteriorated and he couldn’t walk. But he didn’t stop carrying around the cane. When he eventually died he left the cane with the physio as a thanks for the rubber stopper. The physio then proceeded to dismantle the cane and it turns out that underneath a case, there was an umbrella. (SGHC, Student)*

## ‘POINTS OF VIEW’

*In January of this year a relative of mine went into palliative care. As I did not know anything about this care, I asked my uncle and he said “It’s where you go when they’ve sort of given up on treating you”. And I thought how horrible it was to have a place such as that for those who are now deemed hopeless.*

*Within this project, I have been able to actually understand what palliative care entails and the beauty and hope of the centre. This is important because now I can spread this knowledge. I can let my uncle know that it is not about “giving up”.*

## 'JUST LISTEN'

*Growth – this year I grew as a person by looking at death in a different way.*

*One day, I was waiting for the bus to come at my bus stop so I can go home. As I was waiting a woman came and sat next to me. She asked me a question and I answered but as time passed we started talking and having a full conversation even though I did not know her at all. As time passed I realised that all this woman needed is someone to listen to her and hear her out, and sometimes this was just enough. At first I was scared as I didn't know her but then I knew that she was harmless. This shows my growth as a person as I did listen to her and not let her stay all by herself.*

# 'Making the Last Chapter Reflect the Whole Book'

## *GLCH and GRPCC*

Four main themes were identified:

1. Confidence: improved capacity to discuss end of life issues
2. Invitations: increased opportunities to talk about death and dying
3. Reflections and New Insight: greater understanding of end-of-life issues
4. Social Connection: increased networks to share end-of-life concerns

## ‘INVITATION’ – Tell me your Story

*Since commencing the project, I have realised just how many people want to tell me their story. It seems that starting a conversation, or ‘planting a seed’ in someone’s mind about their last chapter, allows them to talk about things that perhaps they haven’t felt they had an audience for?*

*I have spoken to many people, aged between about 25 and 70, who are very passionate about their last chapter but hadn’t really thought too much about it. I think that people want to talk about their lives, their loves, their passions, their fears – and they want to be heard. I think that these people also fear the response of those around them, especially older family members.*

*Continued...*

*People are speaking to me about their inner-most thoughts, feelings, desires and fears. They see my association with this project as an invitation to talk – and that is what we are aiming to achieve.*

*I think that by allowing people the opportunity to tell their stories, to work through their last chapter piece by piece, they are gaining the confidence to take their chapter to a ‘tougher’ audience. The more people talk about their last chapter, the more conversations that are had, the more that capacity is built within the community to deal with issues such as death, dying and bereavement.*

# 'Pondering Mortality'

*Olivia Newton John Cancer Wellness Centre*

Three main themes were identified:

1. Connecting with Strangers: atmosphere of safety and trust
2. Death is Part of Life: increased death literacy
3. Power of Arts: facilitates participants to tap into their emotions

*I really enjoyed the experience of facilitating a group. I was quite surprised at the level of intimacy achieved in such a short time in the group session and felt some satisfaction at having been a key player in making that happen ... I do not get this level of connection in my usual volunteer work – so, even though it is very satisfying at one level, I rarely come away from an information session feeling that connectivity and shared human experience. It has prompted me to think about doing more of this type of work in the future ... it is a lovely way of demonstrating the therapeutic power of facing your mortality and grief and loss etc. – and reminding us of the power of making meaningful connections and talking about the important stuff. I am thinking now about how I can build this sense of meaningful communication into my volunteer work in an ongoing way. (ONJ Volunteer 4)*



*I was also humbled by the trust shown to us by participants and by their vulnerability in this experience. Trusting someone enough to discuss such personal and difficult themes makes us so very vulnerable, and while it is argued that allowing yourself to be vulnerable actually is a demonstration of strength ....*

*It reminded me of just how much trust members of the public show when they are communicating with volunteers. (ONJ Volunteer 3)*

*People are often anxious about art materials. Facilitator has to not talk, to allow reflective space. Art materials intrinsically part of the exercise – forces people to sit with what they're feeling and to be reflective. "It wouldn't work without the art materials. (Volunteer 4)*

*It taught me about me. I'd be comfortable to go to a session as a participant. Different people are drawn to different materials, postcards, poems, songs. Some people wrote. I don't think the role is for me, but I enjoyed it as a one-off. I learnt about myself [as a facilitator]. (Volunteer 3)*

*There is such a need to bring death back into the family culture of the past; to that place where it is once more OK for most people to die at home with appropriate supports in place, where the body rests in the home and people come to surround the family with love and care. It is more than time to reintroduce death to the living ...*

*This project offers the opportunity for reintroducing dying into life, greeting the many faces of mortality gently, creatively, without compromise and with hope in a caring environment. **I hope it succeeds.** (ONJ Volunteer 2)*

# FINDINGS

## Community Capacity Building with Volunteers

*The focus of most studies of volunteers has been on their contribution to extending palliative care services (Horey et al 2015). That is, volunteers have been used to build the capacity of a service, not the capacity of their communities.*

- Volunteer service model: challenges for volunteer community capacity building (risk management/emotions)
- Program sustainability
- Service delivery model undertaking CCB projects (funding structure, resource allocation, expertise)
- Community partnerships and networks needed for ongoing recruitment

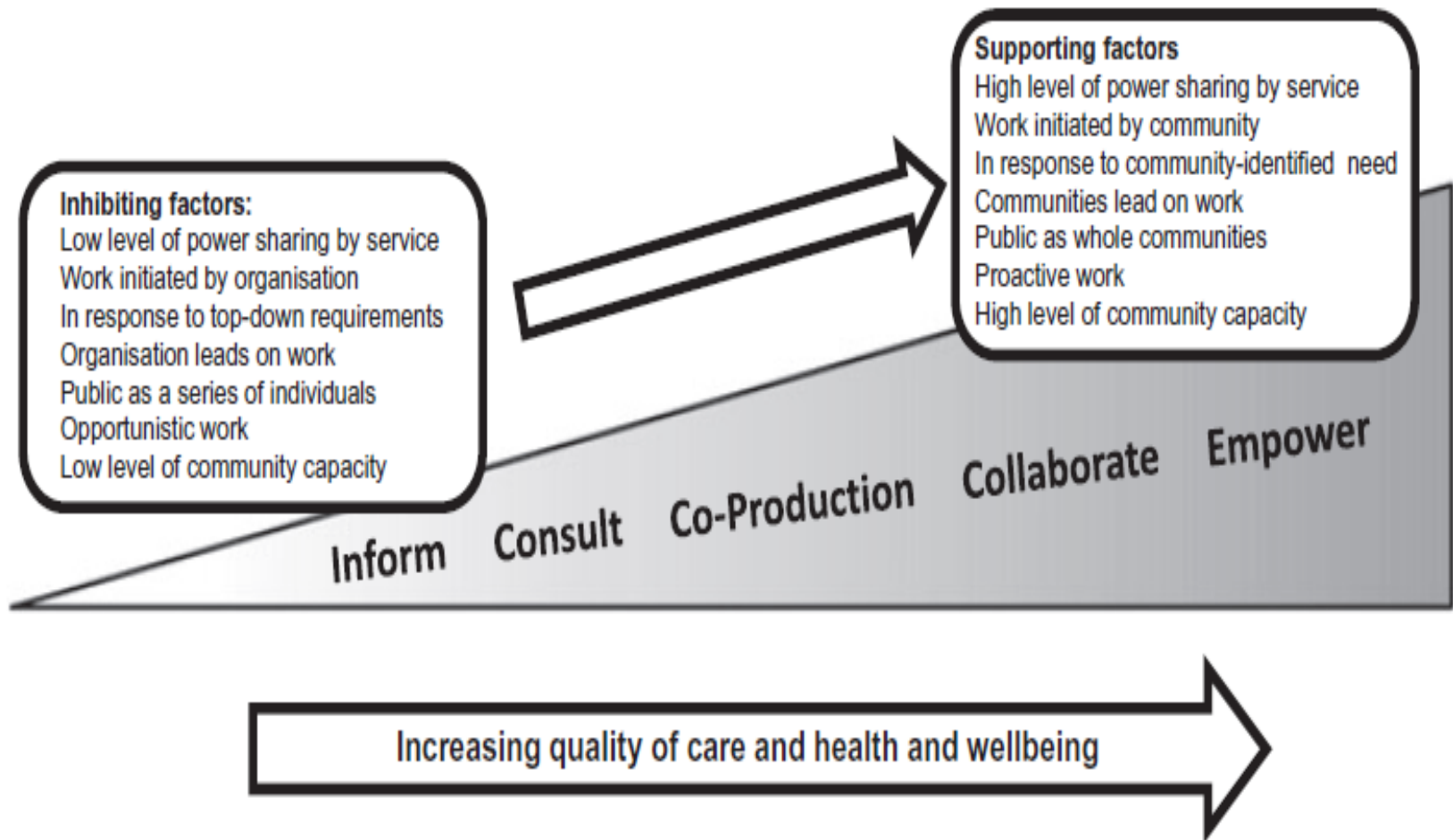


Figure 1. Spectrum of engagement in end-of-life care: developing community capacity.

Sallnow L, Paul S (2014)

# THANK YOU...

Andrea Grindrod, Palliative Care Unit, Department of  
Public Health, La Trobe University

[a.grindrod@latrobe.edu.au](mailto:a.grindrod@latrobe.edu.au)