
An observational comparison of palliative care policy and its implementation in Kerala, India and Victoria, Australia

Project report

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**PAIN AND
PALLIATIVE
CARE
SOCIETY
Calicut**



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1. Executive summary

Around 60% of people who die in Australia and the rest of the world would benefit from receiving palliative care during the terminal stage of their illness (Stjernsward and Clark, 2003). Whilst Australia, and Victoria in particular, lead the world in palliative care service delivery, currently only about 60 to 90% of Victorians who die each year and would benefit from palliative care are receiving it. This situation is worse in rural Victoria with some evidence that 'population based admission rates to palliative care services are 30-50% lower in regional and remote locations than in metropolitan areas' (Aleksandric, Hanson 2010).

Whilst palliative care coverage in much of India sits at around 2%, palliative care coverage in parts of Kerala can be as high as 60 or 80% (Sallnow, Kumar, Numpeli, 2010). This is despite the fact that more than half of Kerala residents live in rural environments (India census, 2011 – see figure 1, section 6) and that Kerala's gross domestic product (GDP) per capita is below the national average (United Nations 2011).

One district in Northern Kerala that has become a model for palliative care service delivery in developing countries is Kozhikode (Calicut) and one community-based organization (CBO) that has taken the lead in this area is the Pain and Palliative Care Society (PPCS).

This observational comparison of palliative care policy and its implementation in Kerala, India and Victoria, Australia was designed to identify principles that may be universal as well as local factors that contribute to the successful implementation of palliative care policy, particularly in rural locations.

The study design consisted of two parts. Part 1 involved a visit to Kerala to undertake fieldwork aimed at identifying factors that contribute to the successful implementation of its palliative care policy. Part 2 involved undertaking a comparative analysis of the Kerala and Victorian palliative care policies and their implementation to identify areas of translational learning between the two contexts.

Data collection methods included:

- Semi-structured interviews with a range of palliative care stakeholders;
- Observation of staff in Kerala undertaking their work in palliative care;
- Reflective journaling throughout the fieldwork phase in India.

The Kerala palliative care model

Similar to Victorian palliative care programs, Kerala's pain and palliative care society's (PPCS) palliative care model consists of three types of care:

1. Inpatient palliative care
2. Outpatient palliative care for patients well enough to travel to the outpatient facility
3. A 24 hour a day, 7 day a week home care service.

The PPCS is committed to providing services to a broad range of clients including long term care clients such as people living with disability and non-communicable disease.

The Kerala model recognizes that much of the support required by people with chronic and terminal illness is social support that can be provided by trained volunteers supported by medical and nursing back-up. Home-based care is the cornerstone of palliative care in Kerala, a primary care approach that is adopted to maximize accessibility

Volunteers form the foundation of Kerala's palliative care program at both policy and implementation levels. Volunteers are drawn from the student population as well as the large population of retired teachers, bank managers and other professionals.

Community based organisations (CBOs) and non-government organisations (NGOs) hold much of the expertise and experience in delivery of palliative care services in Kerala. Policy encourages participation of CBOs in palliative care assessment and service delivery.

Comparison between Kerala and Victoria

Significant social, demographic and political differences exist between Kerala and Victoria including population size, rural/urban population distribution and systems of government. Kerala's three-tier system of local government aims to place greater control of service delivery in the hands of local panchayats (village councils).

In Kerala, government funds coordination of palliative care services, medicines, equipment, programs and some staff. However the state is heavily reliant on CBOs and non-government organisations (NGOs) for palliative care service delivery. In Victoria, the government sector provides funding and clinical leadership including a clearly articulated set of palliative care strategic directions.

Volunteers play an important role in palliative care service delivery in both Kerala and Victoria. However Kerala has arguably developed a more systematic approach to recruitment of palliative care volunteers.

Client profile of palliative care patients differs between the two states, partially because Kerala does not have a well-developed parallel home nursing system for non-palliative care patients. In addition, the observations made in this study suggest that the management of disability as a sector in Kerala may lead to greater demand for palliative care services by clients with disability.

Transferable learnings between Kerala and Victoria were identified in the areas of:

- Enhancing support and awareness of palliative care in Victorian communities
- Systematic expansion of palliative care volunteerism in Victoria
- Further investigation of the management of disability within the Kerala health and community system
- Further consideration of Kerala's heavy reliance on NGOs and CBOs for the provision of basic health care services.

A series of recommendations were made to address these areas (see section 8).

2. Background and literature review

The World Health Organisation defines palliative care as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- *Provides relief from pain and other distressing symptoms*
- *Affirms life and regards dying as a normal process*
- *Intends neither to hasten or postpone death*
- *Integrates the psychological and spiritual aspects of patient care*
- *Offers a support system to help patients live as actively as possible until death*
- *Offers a support system to help the family cope during the patients illness and in their own bereavement*
- *Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated*
- *Will enhance quality of life, and may also positively influence the course of illness;*
- *Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications (WHO, 2011).*

Around 60% of people who die in Australia and the rest of the world would benefit from receiving palliative care during the terminal stage of their illness (Stjernsward and Clark, 2003). Whilst Australia, and Victoria in particular, lead the world in palliative care service delivery, currently only about 60 to 90% of Victorians who die each year and would benefit from palliative care are receiving it (based on number of palliative care clients seen by community palliative care services 2008-2009¹ relative to number of Victorian deaths during the same period [Australian Bureau of Statistics, 2011]). This situation is worse in rural Victoria with some evidence that 'population based admission rates to palliative care services are 30-50% lower in regional and remote locations than in metropolitan areas' (Aleksandric, Hanson 2010).

Whilst palliative care coverage in much of India sits at around 2%, palliative care coverage in parts of Kerala can be as high as 60 or 80% (Sallnow, Kumar, Numpeli, 2010). This is despite the fact that more than half of Kerala residents live in rural environments (India census, 2011 – see figure 1, section 6) and that Kerala's gross domestic product (GDP) per capita is below the national average (United Nations 2011).

The reasons why this may be the case, have been well documented in the published literature and include:

¹ From Victoria's strengthening palliative care policy, Department of Health 2011

- Kerala's unique model of palliative care service delivery, underpinned by the Neighbourhood Network in Palliative Care which delivers palliative care in a non-biomedical, non-institutional based model (Paleri, Numpeli 2005)
- Kerala's decentralized system of government which aims to enhance community participation in government (Institute of Palliative Medicine 2004)
- Kerala's low reliance on government funding to sustain its service delivery programs (Paleri, Numpeli 2005)
- Engagement of volunteers including members of the student population and retired teachers, professionals and others (Graham, Clark 2005).

One district in Northern Kerala that has become a model for palliative care service delivery in developing countries is Kozhikode (Calicut) and one community-based organization (CBO) that has taken the lead in this area is the Pain and Palliative Care Society (PPCS). Established in 1993, the Society's mission is to provide individuals and families coping with a life-threatening illness efficient access to services designed to enhance their quality of life and enable them to receive care in the setting of their choice (PPCS, June 2011). The society has been providing outpatient and home-based care to palliative care patients at the Calicut Medical College since 1994. In 2003, it established an inpatient facility, The Institute of Palliative Medicine (IPM).

In recognition of its contribution to palliative care, the World Health Organisation (WHO) has nominated the PPCS as a Collaborating Centre for Community Participation in Palliative Care and Long Term Care (WHO, 2011).

3. Aim and objectives

Project aim

This observational comparison of palliative care policy and its implementation in Kerala, India and Victoria, Australia was designed to identify principles that may be universal as well as local factors that contribute to the successful implementation of palliative care policy, particularly in rural locations.

Project objectives

1. To identify factors which contribute to the successful implementation of Kerala's palliative care policy.
2. To undertake a comparative analysis of the Kerala and Victorian palliative care policies and their implementation to determine whether learnings from the Kerala palliative care program are applicable within the Victorian palliative care context.
3. To identify potential areas of translational learning between the two contexts.

4. Project description and methods

The study design consisted of two parts:

Part 1

A visit to Kerala to undertake fieldwork aimed at addressing questions including:

- How is the palliative care program being implemented in Kerala?
- How effective is the palliative care program in Kerala from the perspective of staff, volunteers, clients and families?
- What are the key facilitators of the effective implementation of Kerala's palliative care program?
- What barriers exist to the program's effective implementation?
- What is the impact of government policy on delivery of palliative care services in Kerala?
- What is the impact of non-government organizations (NGOs) and community based organizations (CBOs)?
- What is the impact of volunteers?
- What other key factors impact on delivery of palliative care services in Kerala?

Proposed part 1 data collection methods were aimed predominantly at addressing project objective one and included:

- Semi-structured interviews with government employees, staff from NGOs and CBOs, palliative care staff and volunteers (please see appendix one for a full list of stakeholders)
- Observation of staff undertaking their work with inpatients and community-based patients including "shadowing" health workers seeing palliative care clients in the community
- Reflective journaling including recording fieldwork observations, reflections and anecdotal data collected from clients, families, volunteers, palliative care workers and others.

Part 2

A comparative analysis of the Kerala and Victorian palliative care policies and their implementation.

Part 2 data collection methods were aimed predominantly at addressing project objectives two and three and included:

- Analysis of the implementation of Kerala's palliative care policy informed by the fieldwork undertaken in part 1
- Comparison with the researcher's experience of the implementation of the Victorian palliative care policy informed by work previously undertaken which exists in the public domain

- Document analysis and review using policy and other documents available within the public domain
- Identification of any learnings from the Kerala palliative care program that may be applicable within the Victorian palliative care context.

The project was approved by the La Trobe University Faculty of Health Science's Human Ethics Committee on May 11th, 2011 (Reference number: FHEC 11/31) and by the Pain and Palliative Care Society, Calicut's ethics committee on June 1st, 2011.

5. Results

Part 1: Palliative care in Kerala

In undertaking the fieldwork in Kerala, the observational component of the proposed data collection methods emerged as a most effective way of learning about palliative care service delivery in the state. Where possible this was supported and clarified by conversations and semi-structured interviews in English although the level of English fluency of many palliative care workers, volunteers, patients and family members was not sufficient to enable a detailed discussion and analysis of the strengths and weaknesses of the Kerala model in all cases. In relying heavily on observation, the model of palliative care delivery was revealed through stories and personal experiences. The findings of the research are presented here predominantly through those stories.

The IPM model - Hamza's story

When Hamza's head slammed into a solid block following a fall in 2001, the resulting C6/7 cervical fracture left him a quadriplegic. Following his initial treatment in a private hospital, he was offered no further rehabilitation. At the age of 31, Hamza was sent home to lie in bed. After 18 months, Hamza was beside himself with depression and despair. Then, in 2004, he joined IPM's spinal cord injury rehabilitation program. Two or three times a year since then, he and his wife Jasmin have travelled the 73km from their home in Malappuram to receive symptom management and respite care at IPM. Respite care here often means that wives, children, parents and other family members all come to stay and help look after the patient. Looking around him Hamza says, "Everyone is friends here. There is no difference between doctors, nurses and patients". IPM is his second neighbourhood.



The Pain and Palliative Care Society inpatient facility in Calicut

The Pain and Palliative Care Society is a CBO that was established in 2003. The IPM is located in a modern, purpose-built facility beside the Calicut Medical College. IPM delivers a palliative care program that is available to all metropolitan residents of Calicut, India (a catchment of approximately 430,000 people).

Similar to Victorian palliative care programs, the PPCS model consists of three types of care:

1. A 25 bed Inpatient palliative care unit within the IPM
2. Outpatient palliative care for patients well enough to travel to the facility
3. A 24-hour-a-day, 7-day-a-week home-care service.

IPM employs approximately 70 staff including eight specialist palliative care doctors, 22 nurses and administrative, cleaning and other staff.

Inpatients are admitted for:

1. Symptom management
2. Respite care (which often involves family members as well as the client)
3. Terminal care

IPM is committed to providing services to a broad range of clients including long term care clients such as people living with disability and non-communicable disease.

The home care service – Kanarakutty's story

Several kilometres north of Calicut is Cherukulam, a small village whose modest houses reflect the lower levels of wealth in this community compared with others. The men of this village mostly work as farm coolies or coconut tree climbers – a treacherous occupation involving scaling coconut trees up to 30 metres high – I am told one of the highest causes of spinal cord injury in Kerala. Just off the road, in a small, dark room, inside a small, dark house lies 70 year old Kanarakutty. The home care team has come to give him medicines and a food kit. They speak to him in gentle Malayalam. Soon, his son arrives from a neighbouring house and gratefully accepts the food parcel the team has brought for his father. The small bag of rice flour, beans, sugar and other basics must last Kanarakutty one month until the team's next visit.

The 24 hour-a-day, seven-day-a-week home care service has been operational since June 2010, representing an expansion of the previous 8.30am to 4.30pm home care service.

During business hours, four mobile palliative care teams visit around eight patients each who are not able to attend the clinic. After-hours, one of these teams is available for emergency situations including management of symptoms such as bleeding, pain and vomiting. They provide either telephone advice or will visit the patient at any time if required.

During the first six months of the current operational model, the PPCS home care teams saw 832 patients. Provision of food kits and basic support for those in need is seen as an important role of the home care team.



The palliative care team visits a house in Cherukulam

Implementation of Kerala's palliative care policy in Calicut - Saif's story

When Saif was a boy, Mani used to take him fishing. Mani was his neighbour, a few years older than Saif. Living in a village, they knew each other well and spent time together. Mani hadn't had much boyhood himself, having to leave school to support his family after his father, an elephant herder, died. With little education, Mani struggled to provide for his family so he decided to go to Dubai to try to earn enough money to provide a better life for his mother and sister. Five years later he came back. Sick. Very sick.

When the hospital sent Mani home to die, Saif felt helpless. Mani was in pain now and it seemed there wasn't much Saif or anybody else could do to relieve his suffering. Remembering the happy times they'd shared when Saif was a boy made him feel sad now. Soon after, Saif saw the palliative care home care van parked outside Mani's house. He thought they had come to take Mani away. But when he went into his friend's house he saw the palliative care team just sitting, talking to Mani. They talked about his pain and how Mani was feeling and a lot of other things. What Saif remembers most is how much better this visit made Mani look. What a great deal of difference these people could make. Saif hadn't heard about palliative care until then but he decided to find out more about it.

Saif is now the coordinator of Calicut's National Rural Health Mission and has responsibility for implementing the Kerala palliative care policy in his state. Saif doesn't feel so helpless anymore.

The National Rural Health Mission (NRHM) was launched by the Indian Government in 2005 to address gaps in health infrastructure and the significant shortfall in health human resources. Targeted at the local level, It encompasses a range of health care priorities such as maternal and child health, communicable, chronic and non-communicable diseases, mental health and palliative care. The NRHM funds grants for purchasing medicines and equipment for palliative care programs as well as funding district pain and palliative program co-ordinators like Saif.

Palliative care programs being implemented at the PPCS include:

- *Ten/ten* – see Ayaz’s story
- *Tracks we leave* - which provides a mechanism for people to make small financial contributions to the PPCS
- *The million message march to the UN* – a communication campaign aimed at mobilizing community support and political commitment for universal healthcare access (IFHHRO, 2011)
- The *Footprints* project which aims to enable people living with disability and illness to earn an income.

The Chemencheri Palliative Care Home team prepares for rounds:



Neighbourhood and palliative care – Kesavan’s story

Over the front door of Kesavan’s house is a certificate from the Northern Kerala region postmaster general. Issued in 2008, the certificate honors Kesavan’s 33 and three quarter years of “exemplary service” to the department and “wishes him a happy and peaceful retired life”. Inside the house, the retired postman is now receiving the ministrations of the home care palliative care team. His ulcerated toes and oedematous, blistered legs are a legacy of his long-standing diabetes as is the “kidney trouble” the team has come here today to assess.

Kesavan’s son is here with his two children, the youngest playing outside in the rain, his first-week-of-school name-badge displayed proudly on his shirt. A neighbour has also arrived to hear what the palliative care home team has to say. Kerala is a place where neighbours look out for each other, a rare quality that has led to the formation of the neighbourhood palliative care networks on which Kerala palliative care is based.

The nurses patiently address each of Kesavan’s issues in turn. They discover that Kesavan’s wife is currently undergoing treatment for cancer herself. The team finally decides that Kesavan’s kidney trouble will require him to attend palliative care outpatients. It will be up to his two sons and his neighbours to get Kesavan down the narrow, slippery mud track several hundred metres to the road and then by vehicle to the medical college in Calicut – many kilometres away.

The Neighbourhood Network in Palliative Care (NNPC) recognizes that much of the support required by people with chronic and terminal illness is social support that can be provided by trained volunteers supported by medical and nursing back-up for when issues arise that are outside the volunteers’ scope of expertise.

NNPC utilizes Kerala’s highly developed community networks, adopting a social capital approach to the delivery of palliative care services. Communities themselves have taken up the baton of palliative care in recognition of the fact that palliative care is one of the key social issues affecting the people of Kerala. Trained palliative care volunteers live in many villages and districts, caring for their friends and neighbours. The program is aimed at having one trained palliative care volunteer in every home.

Disability and palliative care services in Calicut – Vikru Maya's story

The child's mother hands me one after another of her daughter's drawings – dozens of them. Pictures of peacocks and swans, women in gold saris and Hindu goddesses. The pictures are incredibly beautiful and well executed. In another situation this child might be attending art school. At the end of the display the mother hands me a picture of two swans, their graceful necks arched together in a posture of love – the picture is a gift for me, a stranger from another country, signed by the little girl, Vikru Maya, with love.

Vikru Maya smiles up at me from where she sits on the step beside one of the Chemencheri Palliative Care clinic home care nurses who is giving her cuddles. Vikru Maya is around ten years old – about the same age as my own daughter back home in Australia. Only my daughter is at school today and Vikru Maya hasn't attended school for three years, since a high above knee amputation she had to have in order to save her life after a diagnosis of osteosarcoma. Later, I ask the nurses why she isn't in school. They say it is because of the treatment. I don't understand and nobody can explain it to me.

There are some things that can't be determined through observation alone - such as why a ten year old girl with a disability does not attend school. A number of other people the home care team sees have disabilities - a young man with spinal cord injuries, wheelchair bound and living in a second floor apartment accessible only via a narrow flight of stairs; elderly people who have had strokes or have fractured their hip now lying in bed, being cared for by their daughter or wife or daughter-in-law. Some require the palliative care team to change their catheter or dress their bed sores. Some appear to have dementia. Some are young people who are not working or going to school or participating in life as fully as they might.

I do not have enough information about these people or whether there is more that might be done for them beyond offering palliative care services but seeing this raises many questions for me about the approach to disability in Kerala.

Since 2007, both Australia and India have been signatories to the United Nations Convention on the Rights of Persons with Disabilities. Signatories are required to promote, protect, and ensure the full enjoyment of human rights by persons with disabilities and ensure that they enjoy full equality under the law (UN, 2011).

Anil Paleri, one of the PPCS directors has written:

When a community takes interest in looking after its members who suffer from chronic as well as incurable illnesses, it often finds it difficult to restrict care to people with only certain diagnoses. Volunteers working in the community detect suffering and the clinical diagnoses are of secondary importance to them. So the types of people who are referred to the palliative care units include those with cancer, HIV/AIDS, paraplegia, stroke, problems of old age and debility, psychiatric illnesses, chronic airway diseases, etc.

Often the expertise and resources to look after these patients is found in places other than palliative care programmes in the community (Paleri, Mathews, 2005).

Volunteering – Ayaz’s story

It was Ayaz’s teacher who encouraged him to attend the one-day introduction to palliative care course, targeted at college students and run by PPCS. “I was at that stage in my student life when I could have gone off track”, Ayaz says. But after attending the course, he and a number of other students saw that becoming involved with palliative care was worthwhile not only for the patients but also for themselves.

At first they started collecting money in empty soft drink bottles which they placed around the college – one in every classroom. Then they started going to the classrooms and telling the other students about palliative care. After that they attended a three day “train-the-trainer” camp run by PPCS where like-minded college students with an interest in palliative care came together to develop ideas for increasing their community’s involvement in palliative care.

From this work the 10/10 program evolved. Students pledge to spend ten minutes a day talking about palliative care and raise 10 rupees (about 20 cents) a day to fund palliative care services. 10/10 was launched on the 10th of October 2010 and is steadily growing across college campuses.

Ayaz has graduated now and will soon be going to Dubai where his brothers before him have gone to establish a career in commerce. Ayaz is determined that he will continue his work in palliative care and sees this as an opportunity to further expand his networks and help even more people than he could as a student.

Volunteers form the foundation of Kerala’s palliative care program. Kerala palliative care policy supports this structure with one of its two-year aims being to train at least 300 palliative care volunteers in each district.

Volunteers are drawn from the student population as well as the large population of retired teachers, bank managers and other professionals. In Kerala government employees retire at the relatively young age of 55 which provides a potentially large supply of highly qualified and skilled volunteers. These skills are utilized for palliative care clinic administration as well as in the volunteers’ work with patients.

All palliative care volunteers undergo training and are supported by a network of doctors, nurses and other staff.

Part 2: Comparative analysis of the Kerala and Victoria models

The Victorian model

An in-depth evaluation of Victoria's palliative care model and policy implementation was undertaken by the Victorian Government Department of Health (DH) for its 2011 policy release. The newly released palliative care policy contains detailed information regarding the way in which Victoria's palliative care policy is currently being implemented.

In summary:

- Palliative care in Victoria is delivered in a number of settings including people's homes, acute health services and specialist services
- The Victorian policy outlines seven strategic directions for palliative care service delivery for the next four years. These involve providing quality, coordinated care that places clients and their carers at the centre of service delivery
- Regional leadership, coordination and planning are key roles of the palliative care consortia which were established in each departmental region as a cornerstone of the 2003 palliative care policy. All funded palliative care services, as well as other stakeholders, are members of their regional palliative care consortium. The operational costs of the consortia are funded by the Victorian government
- The Victorian Government funds the majority of public palliative care services
- Statewide clinical leadership in the implementation of policy directions and program initiatives is through the Palliative Care Clinical Network (PCCN), auspiced by the Victorian government cancer and palliative care unit
- Together, the consortia and the PCCN are responsible for implementing the service delivery framework as well as communication, capacity building and clinical service improvement initiatives (Victorian Govt, 2011).

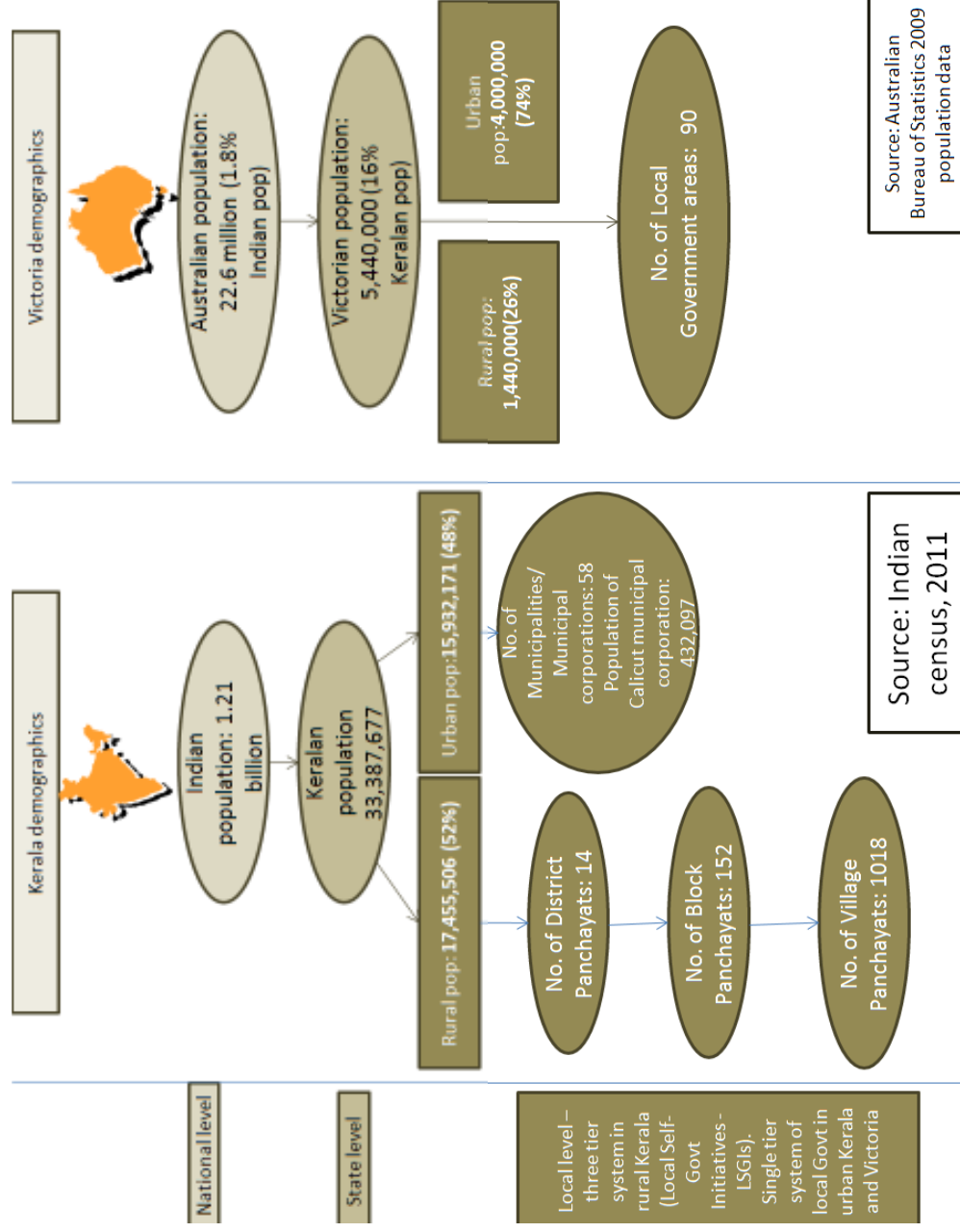
In addition it should be noted that Victoria is serviced by an extensive network of district and bush home nursing services. These services see clients in their homes, predominantly for non-palliative nursing care. Some of these services are also responsible for delivering specialist palliative care services.

Demographic comparison of Kerala and Victoria

Key demographic differences between Kerala and Victoria include:

- India's population is around 53 times Australia's and Kerala's population is around 6 times Victoria's
- Kerala's population comprises 2.7% of the total population of India whilst Victoria contains 24% of the Australian population
- The Victorian population is predominantly urban (74%) whilst more Keralans live in rural than urban areas (52%:48%)
- Kerala has a decentralized system of government with the aim of placing more control over social governance in the hands of local panchayats (village councils). This results in a three-tier system of government in rural areas. These tiers are referred to as Local Self-Government Initiatives (LSGIs).

Figure 1: Summary of some of the key demographic differences between Kerala and Victoria



Policy comparison

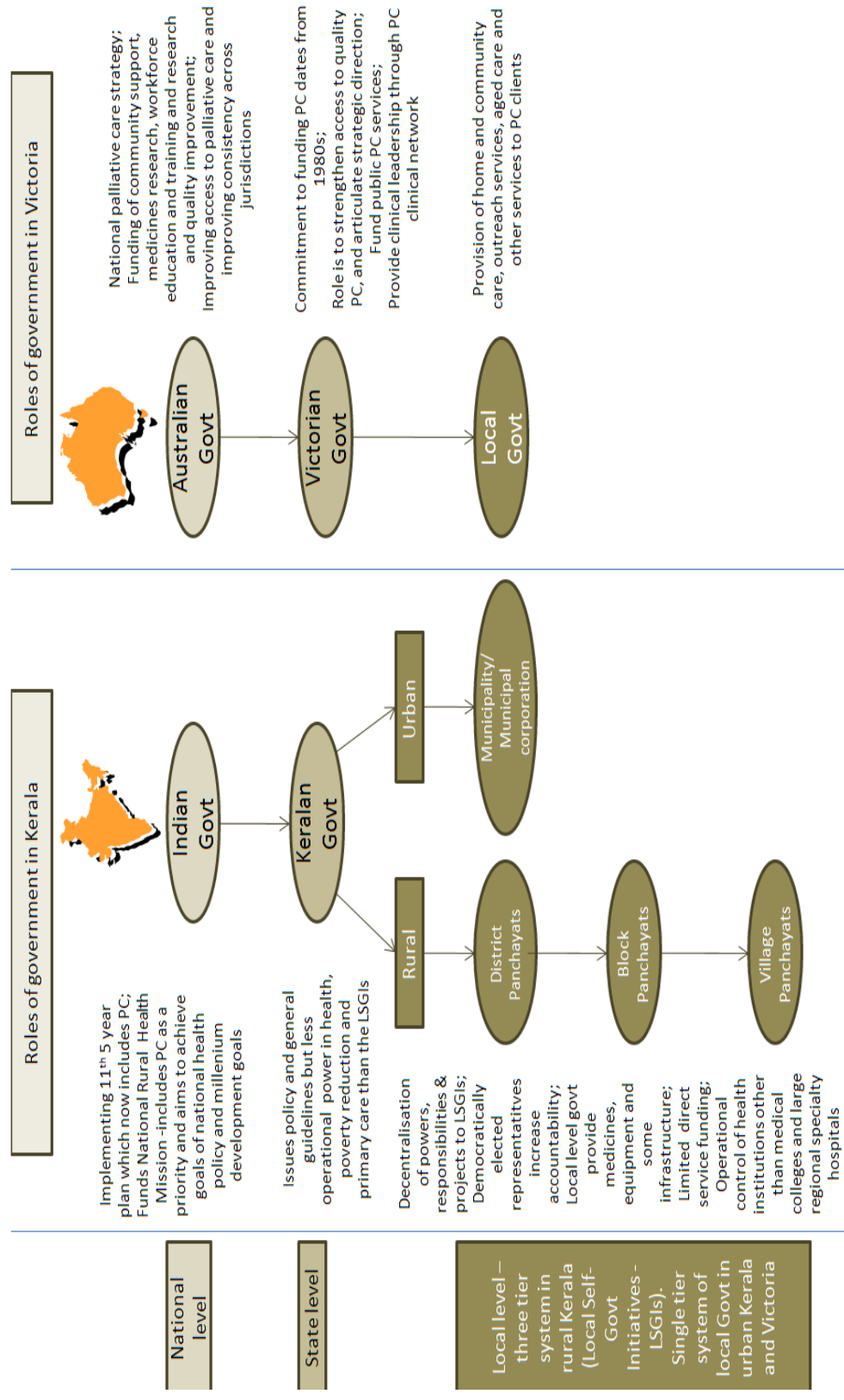
Table 1 provides a comparison of the Kerala and Victorian palliative care policies and their implementation.

Policy feature	Kerala palliative care policy	Victoria palliative care policy
Policy name	Pain and Palliative Care Policy for Kerala	Strengthening Palliative Care: Policy and strategic directions 2011 – 2015 (currently in draft format)
Date of policy release	2008	Originally released 2003 (Revised 2011)
Definition of palliative care	WHO definition 2002 (consistent with 2010 definition)	WHO definition 2010 as defined in section 4 of this report
Policy aim	To provide palliative care to as many needy people as possible in the state	Expand capacity, address gaps in the service system, raise community awareness about death and dying
Service delivery setting	Home-based care is the cornerstone of palliative care – a primary care approach is adopted to maximize accessibility	Services are delivered in a range of settings from people's homes to acute health settings to highly specialised settings including dedicated inpatient and day hospice services
Role of State Government as outlined in policy	To work in harmony with CBOs and NGOs. Integration of pain and palliative care concepts and skills into existing specialty services of government hospitals; integration of palliative care services into routine health care in the state	Strengthen access to quality palliative care, articulate strategic direction, fund public palliative care services and provide clinical leadership
Role of palliative care services	Provide predominantly home-based treatment including social support and rehabilitation where necessary. Work with LSGs to improve care received by patients	To provide quality, coordinated, consistent, evidence-based care. To be active members of their regional consortium
Role of volunteers	Around 4000 trained volunteers in palliative care in Kerala. Health professionals also volunteer their time to palliative care. Role involves: Direct client service provision particularly in the psychosocial and financial support domains; fundraising, clinic administration and organizing rehabilitation programs. Volunteers can be retired professionals such as teachers and bank managers and many have high level administrative and organizational skills (Paleri, Numpeli 2005)	Comprise approximately two thirds of the palliative care workforce (DHS, 2007). Role involves: Provision of physical and psycho-social support within the client's community. Guided by a set of volunteer standards linked with the palliative care policy. A structured training package for palliative care volunteers has been developed by Palliative Care Victoria
Role of communities and CBOs as outlined	CBOs and NGOs hold much of the expertise and experience in delivery of palliative care services in Kerala. Policy encourages participation of	To have an awareness of death, dying and loss, and to support clients and carers

in policy	CBOs in palliative care assessment and service delivery	Peak bodies have role in education, information and referral – less role in direct service provision. Some services provided by CBOs
Timing of introduction of palliative care	Implement palliative care from time of diagnosis, even if disease is amenable to curative treatment	Continuum of curative and palliative care
Funding	Provision for budget allocation from directorate of health service, directorate of medical education, LSGIs, national health programs and employees' state insurance schemes. No additional staff to be created - existing staff including government doctors and nurses to be trained and deputed for palliative care. Government funding of CBOs and NGOs service delivery is discouraged as it is believed that this can lead to reduced local support for programs. Most of the funds for community palliative care service delivery are raised through small donations – micro-funding	Victorian government commitment to funding palliative care dates from 1980s. Victorian government funds service delivery, regional coordination and planning as well as education and research. Provision of government funding to support NGOs and peak bodies providing palliative care research, training and services (CBOs frequently attract additional funding of up to 20% from non- government sources such as bequests)
Clinical leadership and palliative care training	National training conducted by Indian association of palliative care. Local training courses conducted by CBOs. CBOs hold much of the palliative care clinical expertise and experience in training and clinical leadership Kerala policy direction aims for more training centres in government sector, capacity building in CBO and NGO sector and development of guidelines for training programs	Australian and Victorian governments fund programs in palliative care training. Peak bodies and academic centres play an important role in information provision, advocacy, research and training. Statewide clinical leadership in the implementation of policy directions and program initiatives through the PCCN
Expected policy outcomes	Policy contains short and long term action plans with measurable outcomes in areas including training, availability of medicines, involvement of CBOs and LSGIs, services in government hospitals, guideline development	Access to appropriate palliative care services for all Victorians; Seamless, quality care informed by research; Community support for Victorians with a life-threatening illness and their families and carers
Bereavement support	Bereavement visits form a part of the PC home care team's role	Supporting families and carers in bereavement is a key component of best practice palliative care (DH, 2011)

Role of government

Figure 2: Summary of some of the key roles of different levels of government in Victoria and Kerala.



6. Discussion

Key points of difference between implementation of palliative care policy in Kerala and Victoria.

Kerala's three-tier system of local government aims to place greater control of service delivery in the hands of local panchayats (village councils). As in Victoria, government representatives are democratically elected and therefore accountable to their constituents for their achievements. In order to be re-elected, representatives must be in tune with constituents' needs, palliative care being a need that has been clearly articulated in Kerala. Arguably though, this three-tier system of government may result in a more cumbersome bureaucracy and a higher taxation burden.

In Kerala, government funds coordination of palliative care services, medicines, equipment, programs and some staff. However the state is heavily reliant on CBOs and NGOs for palliative care service delivery. Micro-funding (small donations of 1-10 rupees) is the major method by which organizations like the PPCS fund staff, services and programs. In India overall, public spending on health is low (1% of GDP) whilst private spending on health is high. According to India's current five year plan, households spend on average 5-6% of their expenditure on health (Government of India, 2008). Much of the clinical leadership, expertise and experience sits within the CBO and NGO sector.

In Victoria, the government sector provides funding and clinical leadership including a clearly articulated set of palliative care strategic directions. These directions have been driven by government and developed in conjunction with the sector. They will set the agenda for the delivery of palliative care services in Victoria for the next five years and beyond. Development of Kerala's palliative care policy was heavily driven and influenced by CBOs.

Volunteers play an important role in palliative care service delivery in both Kerala and Victoria. Victoria has developed a set of volunteer guidelines linked to its palliative care policy. Both states have formalized volunteer training programs. However Kerala has arguably developed a more systematic approach to recruitment of palliative care volunteers. Programs have been developed that target students in particular, with the aim of raising student awareness and knowledge of palliative care. Volunteers play an important role in fundraising, clinic administration and program development as well as providing hands-on support to palliative care patients in their communities. Kerala has set specific targets for recruitment of volunteers in the state and in each community.

Another key difference between Victoria and Kerala is client profile. In the absence of a parallel home nursing system like the bush and district nursing systems that operate in Victoria, some of the home nursing workload and care of disability clients falls to palliative care teams in Kerala. In addition, the observations made in this study suggest that, in Kerala, the treatment of disability in general, may result in lower levels of participation in society by Keralans with disability than in Victoria. This could result in disability clients requiring palliative care support in greater numbers than Victorian clients. This an initial observation only and requires further investigation.

7. Conclusion

Learnings from Kerala

Kerala's political and social culture is unique in a number of ways. Kerala has managed government decentralization through the panchayat system more effectively than has been achieved in other parts of India leading to enhanced community engagement. Its strong culture of community involvement and accepting responsibility for neighbours is another unique aspect of Keralan society. Much of the state's achievement in palliative care is attributable to these factors. Kerala's health system and policy approach is one that encourages active involvement of CBOs and NGOs in service delivery. Given these factors, it is not necessarily realistic to expect that the Kerala palliative care model is replicable in Victoria. However, there are a number of lessons Victoria could take from Kerala.

The key priority identified by the Victorian government under strategic direction 7 of its palliative care policy - Ensuring support from communities is: *Strengthen Victorians' awareness and understanding of death, dying and loss and ability to support people with a life-threatening illness and their carers.*

The PPCS home care teams go about their duties using distinctly marked vehicles that carry the name of the service and the name of the organisation that sponsors the vehicle. They are attention-grabbing, particularly in a state in which private vehicle ownership is relatively low (Aneez, 2010). Similarly, in Victoria, some district and home nursing service vehicles are marked. There is some evidence from this project that these vehicles serve an important awareness-raising function in Kerala. A simple and relatively inexpensive way of raising awareness, marking palliative home-care vehicles, may be an exercise worth considering in Victoria.

Kerala has been highly effective in mobilizing its student population as a source of palliative care volunteers. In general, the student population is largely comprised of youths who have yet to commit to family and career and whose study and work commitments may allow them additional time for volunteering. In Kerala, engagement efforts have targeted student bodies so that palliative care volunteerism becomes institutionally embedded. Therefore as each generation of students moves on, the capacity to recruit new volunteers remains with the colleges. Other sources of volunteers in Kerala include retired professionals such as teachers and bank managers.

Expansion of the palliative care volunteer sector may be possible in Victoria through developing targeted programs aimed specifically at school, university and college students. Many Victorian schools currently have social justice programs and there is evidence of an increasing trend towards ethics, social justice and values education in Australian government and non-government schools (Australian Government, 2005). At present opportunities may exist for developing palliative care awareness programs for schools and linking into schools through these aspects of the curriculum.

In rural Australia in particular there is already a strong service club culture (Lions, Apex, Rotary). These clubs could be targeted with the specific purpose of embedding palliative

care volunteerism into their activities. In Kerala, retired professionals working as palliative care volunteers undertake a range of tasks including clinic administration, provision of psychosocial support to clients and fundraising.

As one volunteer interviewed for this project said: “Everyone can offer palliative care. From taking a meal to a person’s home when they are sick to asking how they are after their treatment. This all constitutes palliative care.” When a palliative care mentality is embedded into a culture, people see how they can play a role in caring for other members of their community.

Learnings from Victoria

Kerala’s progress in palliative care has been remarkable. Its achievements have been significant in a short time and include:

- Establishment of more than 100 palliative care units across the state
- Development of palliative care training programs for volunteers and professionals
- Recruitment and training of more than 4000 palliative care volunteers (Government of Kerala 2008).

Every health care system aims to do its best with the finite resources available. Kerala is doing better than many around the world and leading the way in health and palliative care in India. It is therefore unfair and possibly unhelpful to look at Kerala’s health care system through the prism of western eyes. However Kerala has high expectations of itself. It prides itself on its almost 100% literacy rates, on its population’s high levels of education participation and on having the best health care system in India. Under the NRHM it is implementing programs not just in palliative care but in maternal and child health, mental health, communicable and non-communicable diseases and chronic illness. It is in this context that the following observations are noted.

Disability is one area in which there appear to be some gaps in Kerala’s health care system. A range of people with disabilities were observed to be participating less fully in life than their disability might have warranted. Others, particularly older Keralans, having suffered strokes or fractured hips are not participating at all. Sent home to lie in bed, they have become increasingly debilitated to the point where their quality of life appears to be compromised and some pose a significant burden to family and carers as well as increasing the demand for palliative care services.

When discussing translational learnings it may be more appropriate to see these in terms of what Kerala can learn from Kerala rather than from Victoria. The success it has had in implementing its palliative care program may be transferable to areas such as disability should this be considered a priority. The benefits would be many – increased participation in schooling and work for people with a disability, reduced economic burden on families and society, increased quality of life for both patients and their families as well as reduced demand on palliative care service for these patients, thereby freeing up resources for other patients.

A further observation that applies to the health care system as a whole, but particularly to palliative care, is Kerala's heavy reliance on NGOs and CBOs for the provision of basic health care services. Whilst it is viewed locally that this reduces reliance on government funding and therefore leads to a more sustainable funding model, it also may represent some risk to health care service delivery in terms of access, regulation of service provision, monitoring, standards and other factors.

A general observation regarding India's health system noted in its current five year plan is that:

The system lacks a real and working process of monitoring, evaluation, and feedback. There is no incentive for those who work well and check on those who do not. Quality assurance at all levels is not adhered to due to lacunae in implementation (Govt of India 2008, page 65).

A move towards greater government involvement in the sector may lead to a more consistent, standardised service with greater equity of access, potentially allowing all Keralans access to a Calicut-standard service.

Enhancement of upstream public health measures such as health promotion activities are a challenge for all nations but have demonstrable benefits along a range of domains. One example of an area in which public education and health promotion may have benefit in Kerala is in education around first aid management of spinal cord injury. There is potential for this type of campaign to reduce the devastating outcomes of spinal cord injury that have resulted for people like Hamza.

8. Recommendations

These recommendations have been developed in response to the observations and areas of translational learning identified in this study:

Recommendation one: Victoria may consider introducing marked palliative care vehicles for the provision of home care, similar to those currently used by many home nursing services.

Rationale: There is anecdotal evidence that some people's initial awareness of palliative care resulted from identifying vans used by the palliative care home care teams visiting their villages.

Recommendation two: Victoria may consider developing palliative care awareness-raising programs targeting school, university and college students, potentially through school social justice programs or creating links with university and college student unions.

Rationale: School and college students in Australia are a largely untapped resource in terms of community capacity and volunteerism. Evidence from Kerala indicates that students have the willingness and capacity to organize themselves into a strong contributor to palliative care and other public health programs.

Recommendation three: That further investigation of the management of disability in Kerala be considered with a view to applying palliative care principles to the disability sector

Rationale: There was some observational evidence that Keralans with disability were contributing less fully to Keralan society than their disability warranted.

Recommendation four: That Kerala considers the relationship between government and CBOs and the role of CBOs in delivery of health services. This may involve development of guidelines and quality assurance processes that enhance standardisation of service delivery as well as equitable access to services for all Keralans.

Rationale: Kerala's heavy reliance on CBOs for delivery of palliative care service may be a barrier to a standardized, high quality service accessible to all Keralans.

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Appendix 1 – List of stakeholders

Please note that many stakeholders refer to themselves only by their christian or surname.

Pain and Palliative Care Society - Calicut

Name	Role
Babin	Student Volunteer
Junais	Student Volunteer
Sandhya	Volunteer doctor
Suresh Kumar	Director, Pain and Palliative Care Society
Anil Pateri	Director, Pain and Palliative Care Society, Palliative care physician
Meena Vaidyanathan	Volunteer
Saif	IPM Project Manager
Nisha Krishnadas	National information manager -
Nishanth	Palliative care doctor
Geetha Marathakkot	CEO Pain and Palliative Care Society, Senior Pain and Palliative care nurse
Ayaz	Student volunteer
Abdul Latheef	Deputy Mayor, Calicut Corporation

Home-care teams

Name	Position
Institute of Palliative Medicine	
Sreeja	Nurse
Dhanya	Nurse
Ashokan	Volunteer
Chemengeri Palliative Care Clinic, Pookart	
Girija	Nurse
Valsala	Nurse
Mini	Nurse
Davood	Coordinator
Rajhavam	Volunteer
Radhakrishnan (The master)	Volunteer (retired teacher)
City Clinic, Calicut	
Shahida	Palliative care doctor
Sreeja	Nurse
Sulochana	Nurse
Agnes	Nurse
Sheeba	Coordinator
Pratap Singh	Volunteer coordinator

Victoria

Name	Position
Bruce Rumbold	Director, Palliative Care Unit, School of Public Health, La Trobe University
Amanda Bolleter	Acting Manager, Palliative Care Unit, Department of Health
Sue Salau	Volunteer Coordinator, Palliative Care Victoria
Kerrie Noonan	Founder and Director, Ground Swell Project (NSW)

Appendix 2 – List of abbreviations

ABS	Australian Bureau of Statistics
CBO	Community Based Organisation
DH	Department of Health, Victoria
DHS	Department of Human Services, Victoria
GDP	Gross Domestic Product
IFHHRO	International Federation of Health and Human Rights Organisations
IPM	Institute of Palliative Medicine
LSGIs	Local Self-Government Initiatives
NGO	Non-Government Organisation
NNPC	Neighbourhood Network in Palliative Care
NRHM	National Rural Health Mission, India
PPCS	Pain and Palliative Care Society, Kozhikode
UN	United Nations
WHO	World Health Organisation