



**Palliative
Care
Queensland**

Palliative Care Place Stories

Project Overview

Palliative Care Queensland Incorporated
ABN 48 047 803 923

Introduction

Palliative Care PlaceStories is a web based software system that will enable people affected by terminal illness in Queensland to share their individual story and experiences about death and dying. The project will result in the development of a customised, web based software platform to provide patients and families with a simple process for creating and publishing their stories on-line, and in so doing, allowing others to share their powerful and moving life experiences in relation to death and dying. It is hoped that by facilitating this story telling process within a professional network and supportive environment, the process of grief itself is facilitated. The project will improve the awareness and understanding of palliative care amongst clients and the broader community. As a therapeutic tool, the program will also support the work of the clinicians who provide grief, loss and bereavement support.

Project Aims

The primary aim of the Palliative Care PlaceStories project is to enable people affected by terminal illness to tell share their stories about palliative care death and dying, and to document their experiences of the sector.

The secondary aim of the Palliative Care PlaceStories project is to establish over time, a growing and accessible repository for qualitative palliative care knowledge, including data relating to area specific strengths and deficits. In the future this data could be used to underpin the development of other Palliative Care Queensland (PCQ) projects and initiatives, and to inform future service and policy development.

A further aim of the Palliative Care PlaceStories project is to explore the potential in the future to scale up this system to support similar story sharing and communication in the Palliative Care at a national level. In this context, as well delivering specific outcomes and services for Queensland communities the project has the potential operate as pilot stage for future national initiatives.

Collaboration

The project will be managed by PCQ with external specialist support and consultancy provided by Feral Arts. (www.feralarts.com.au)

PCQ is the peak representative body for palliative care in Queensland, its vision being to facilitate the provision of quality care at the end of life for all Queenslanders. PCQ is a member organisation of the Palliative Care Australia network, and as such, its major aim is to raise awareness of palliative care and issues relating to death and dying, within the general community.

Feral Arts is a nationally recognised not-for-profit cultural development company building custom software systems to maximise the use of cultural assets, including stories, histories and networks, in order to enhance the creativity and sustainability of benevolent community based organisations such as PCQ. Feral Arts is one of eleven community cultural development companies funded nationally by the Australia Arts Council as a Key Producer under its community partnerships program.

Consultation

In developing this proposal, we undertook extensive consultation with our partners and colleagues from across the State. The following individuals have directly endorsed the plans for the Palliative Care PlaceStories Project:

Mr John-Paul Kristensen, CEO, Palliative Care Queensland
Prof Patsy Yates, Director Research, QUT School of Nursing and Midwifery
Dr Louise Welch, Director Sunshine Coast Palliative Care Service
Dr Matthew Cooper, General Practitioner Mapleton Medical Centre

Ms Margaret Deane, CEO Qld Aged and Disability Advocacy
Mr Neal Price – Arts and Health and digital storytelling specialist
Ms Sarah Moynihan and Mr. Norm Horton, Directors, Feral Arts

Implementation Plan

Phase One – Development of the Web-Based Platform

Utilising the existing 'PlaceStories' software system (www.placestories.com) and pursuant technology as a starting point, PCQ will collaborate with Feral Arts to develop a customised online platform supporting story telling and communication for palliative care clients, their families and allied healthcare professionals within the context of end of life. The development of this platform will combine technical input from Feral Arts and clinical and scientific input from PCQ. Both parties will utilise current best practice project management guidelines to identify and mitigate risks throughout this process.

Phase Two – Development of an Education and Training Package

PCQ will engage an education and training consultant to develop and deliver an educational and training package for both consumers and clinicians. This package will include an on-line educational module for both consumers and clinicians, as well as a face-to-face module that will be delivered to targeted groups throughout the state.

Phase Three – Delivery of a Statewide Education Initiative

During this phase, the project will be launched. The education and training consultant, accompanied by a senior representative of PCQ, will travel throughout the state to deliver education packages to social workers, psychologists, counsellors, pastoral and spiritual care workers, and all other clinicians whose primary role is to provide grief and loss support to Queenslanders affected by terminal illnesses. Sessions will take place in Mount Isa, Cairns, Townsville, Mackay, Rockhampton, Bundaberg, Sunshine Coast, Gold Coast, Toowoomba and Brisbane.

Phase Four – Project Evaluation

PCQ will engage the services of the palliative care research unit of the Institute for Health and Biomedical Innovation at Queensland University of Technology to evaluate the project. This evaluation process should provide the data required to determine whether the project has had a positive impact on consumers who have accessed the program. Information from this process will be used to determine whether it is appropriate to continue the project for a further three year period, in which case, longer term funding sources will be investigated.

Evaluation data from this project will be gathered using the following methodologies:

- Post training session evaluation surveys
- Post implementation surveys (on-line)
- Post implementation interviews (telephone)
- Consumer feedback surveys (on-line)
- Consumer interview (telephone)

These evaluation methodologies will result in the collection of both qualitative and quantitative data, which will be reviewed externally. This external evaluation should indicate whether the project was successful in improving the quality of life of the patients and families who participated by sharing their story.

Supporting Data

The provision of additional psycho-social support

In relation to the primary objective of the project, that being to provide patients and families with a means to tell their story about death and dying, no statistical data is available to demonstrate that the current quantum of loss or bereavement support services in Queensland does not meet the current demand for these services. A statewide project to map palliative care and end of life services, and to measure the quantum of services statewide was completed in March 2011, however this data has not been made available to the Queensland public.

In July and August 2009, PCQ conducted forums for health professionals working in the palliative care and end of life care sector. These forums took place in Cairns, Townsville, Sunshine Coast, Toowoomba, Gold Coast and Brisbane, and were well attended by the relevant sector clinicians. During these forums, participants were asked whether the allied health services in their region were adequate to meet the needs of terminally ill patients and families. Many clinicians indicated that the demand for grief, loss or bereavement services in their region outweighed the supply.

Anecdotal evidence gathered by PCQ from non-government providers of palliative care also supports the assumption that the demand for grief and loss counselling and support services outweighs the availability of services. Agencies such as Karuna Hospice Service, Cancer Council Queensland Counselling Service, Hopewell Hospice and St Vincent's Brisbane experience a significant demand for services of this type. In all cases, demand for these services grows annually, and resourcing is not adequate for services to meet this growing demand.

In relation to the national demand for psycho-social services, and in particular counselling services, according to the Australian Bureau of Statistics Labour Force Survey, the counselling profession had grown at a rate of 23.1% in the two years preceding the survey, the counselling profession outgrowing all other professions by 200% with the counselling sector having the fastest rate of growth for the next 5 years (www.aipc.net.au).

Community Benefit and Sustainability

The outcomes of the project will be disseminated throughout the palliative care and generalist end of life networks by PCQ and Palliative Care Australia. The evaluation report will be published in the PCQ newsletter, and circulated to all PCQ members and industry stakeholders, including Queensland Health. The Palliative Care PlaceStories system will be utilised by both PCQ and the broader palliative care sector. Sustainability and currency from a technical standpoint is provided by Feral Arts, with hosting, updates and licensing covered until the end of 2013.

Information from the project (patient and family stories) will be utilised wherever possible by PCQ to raise the profile of the sector, and to highlight the strengths and deficits of the system. In all instances, use of the patient and family stories will require individual authorisation.

Project Budget (set Nov 2009)

<i>Item</i>	<i>Cost</i>
System & Software Development and Licensing	46,200
Travel, Accommodation and Venue Costs	19,141
Training Consultancy	19668
Training Program	3300
Evaluation/Reporting	11,000
<i>Total</i>	<i>\$99,308</i>