BRISBANE SOUTH
PALLIATIVE CARE COLLABORATIVE

Queensland Government

Griffith UNIVERSITY

Caring Safely at Home Project

Summary Report
July 2007 – May 2010

Supporting Carers of People Requiring Palliative Care At Home

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1. Executive Summary

Project Statement

The Caring Safely at Home (CSAH) project was managed by the Brisbane South Palliative Care Collaborative (BSPCC), in partnership with the Centre for Palliative Care Research and Education (CPCRE) and Blue Care with funding from the Australian Government Department of Health and Ageing (DoHA) under the *Supporting Carers of People Requiring Palliative Care at Home* initiative. The purpose of the project was to enhance the capacity and confidence of lay carers to help palliative patients to remain at home, with timely access to symptom control.

Palliative care services strive to support patients to live and to die within their individual setting of choice, usually home, with optimal symptom control and with a pattern of care that is also supportive of caregivers. The likelihood of patients remaining symptomatically well managed at home usually depends upon input from lay carers who may be required to administer subcutaneous medications. Bereaved carers report their ability to provide injections adds value to patient care; nonetheless many report the need for education and resources to assist them to confidently manage this aspect of their care giving role. [1] This project developed, trialled and evaluated an educational and resource package that supports lay carers to manage subcutaneous injections.

Project Scope

The scope of this project was firstly to develop a standardised education and resource package, which aimed to enhance lay carers' confidence and ability to safely manage and administer subcutaneous palliative medications in the home. Requirements of the package were that it incorporated consensus-based best practice and that it was compliant with legal and Queensland jurisdictional constraints. Secondly, the package was piloted and evaluated across urban, regional and rural geographical areas within South East Queensland. Finally, a randomised controlled trial (RCT) was conducted to examine possible differences in outcomes for lay carers in terms of overall confidence when assessed across the three following conditions:

i. The lay carer prepared, labelled and stored daily breakthrough medications for subsequent injection by the lay carer
ii. A registered nurse (RN) prepared and labelled daily breakthrough medications for subsequent injection by the lay carer
iii. A clinical trial pharmacist prepared and labelled daily breakthrough medications for subsequent injection by lay carers.

Project Outcomes

Guidelines for the Handling of Medication in Community-Based Palliative Care Services in Queensland.

At the commencement of this project it was identified that many RNs were unclear about the legal, jurisdictional and scope of practice issues related to the preparation and administration of subcutaneous injections in the community. In response to this, the BSPCC and the CSAH project co-ordinator finalised the development of the 'Guidelines for the Handling of Medication in Community-Based Palliative Care Services in Queensland'. [2] These guidelines are compliant with the *Health (Drug & Poisons) Regulation 1996,* the *Guardianship and Administration Act 2000* and the *Powers of Attorney Act 1998;* and represent consensus-based best practice in palliative care. The guidelines were endorsed by Queensland Health (QH) Environmental Health Unit, QH Chief Health Officer in October 2008, and QH Patient Safety and Quality Executive Committee in August 2009. (See Appendix 1)

Standardised Education and Resource Package

A team of clinical and academic palliative care professionals and consumers developed a suite of resources to be implemented within a standardised educational framework that catered for differing adult learning and teaching styles.

The resources, described in Appendix 2, included:

- step-by-step charts illustrating preparation and administration of subcutaneous injections
- a practice demonstration injection device to allow RNs to teach and lay carers to practice injecting
- a colour-coded medication labelling system to enhance safety when providing injections
- a refrigerator (fridge) magnet to enhance the safety of the colour-coding system
- a daily diary for medications injected to enable carers to maintain a medication administration record that could be monitored by health professionals
- a competency checklist for RNs to confirm that carers are competent to manage injections
- a medication booklet entitled 'Subcutaneous Medication and Palliative Care: A guide for caregivers'
- a DVD entitled 'Palliative Subcutaneous Medication Administration: A guide for caregivers'
- a lanyard for RNs showing the colour-coding system and the elements of the standardised education framework.

These resources were given to lay carers when RNs delivered the standardised education package in a one-on-one teaching session. To ensure consistent delivery of the education, RNs were trained in all aspects of the package.

Pilot of Standardised Education and Resource Package

The package was piloted across 24 sites in urban, regional and rural settings across South East Queensland. A total of 217 RNs were trained in the delivery of education and use of the resources, over an 18 month period.

Evaluation of the Standardised Education and Resource Package

The package was evaluated across all sites, quantitatively and qualitatively, using 106 lay carer and 53 RN responses to semi-structured questionnaires.

Lay carers were asked to complete two questionnaires, the first (*Time 1*) was completed immediately after the face-to-face education and the second (*Time 2*) after they had gained experience with subcutaneous injecting. Lay carers ranked their responses to various questions using 7-point Likert scales, where the higher the score, the better the rating. They rated the usefulness of the education and resources as well as their perceptions of confidence, safety, efficacy, satisfaction and stress levels before and after their experience of injecting.

Lay carer global satisfaction with the entire package was high; every ranking mean was equal to or above 5.9 for both questionnaires. Individual aspects of the package were all rated highly (means above 6.0) including the face-to-face education session, the written and illustrated information provided in the packages, the demonstration and supervision while giving a subcutaneous injection, and the DVD. In terms of lay carers' confidence with subcutaneous injection management, means were uniformly high at both times indicating the benefits of the education package in preparing lay carers for the task of administering injection(s).

In summary, the package was perceived by lay carers as being beneficial in terms of subcutaneous medication management. Having access to quality information was associated with a reduction in lay carer stress and increased level of lay carer confidence with

subcutaneous injection administration. Qualitatively, lay carers reported that the colour-coded system assisted them in administering the right drug for the right symptom.

RNs were asked to complete one questionnaire at the end of the study. The questionnaire was similar in content and rating as that used for the lay carers.

RNs also rated the education package highly in terms of overall aspects such as appropriateness to the needs of lay carers and providing the necessary information to allow lay carers to safely prepare and administer subcutaneous injections. Similarly they indicated that the issues relevant to subcutaneous injections of palliative care medications had been well explained, and that the components of the education package provided useful resources for lay carers. The lowest rating of the RNs, concerned the ease of delivery of the education session.

RCT: Lay Carer Confidence in Administration of Injections According to Who Prepared the Injections

The RCT explored whether lay carer confidence differed according to who prepared the medication(s). Analysis of results was based on 1306 injections delivered by a total of 94 carers. Analysis of variance indicated that there were no significant differences between groups in terms of level of confidence for medication injection. However, over time, level of confidence increased significantly for every group, though there were no significant differences between the groups.

An audit of the 1306 injections revealed that all injections given contained medications that were appropriate to the symptom reported.

In summary, lay carers can confidently and safely manage subcutaneous medications, regardless of whether the lay carer, the RN or a pharmacist prepares the injections. Confidence with injecting improves significantly with experience.

Project Schedule

The project duration was three years. It commenced in September 2007 and completed 31 May 2010.

Discussion and Conclusions

Results from the CSAH project demonstrate, if lay carers are supported with quality resources and standardised information, they can confidently and competently manage symptoms that require the delivery of subcutaneous medications to home-based palliative care patients. Further, lay carers' confidence with symptom management is not diminished when they, rather than a health professional, such as an RN or pharmacist, prepare the injection. Not surprisingly, when lay carers are well educated regarding symptom management, their levels of confidence increase as they gain experience with preparing and administering subcutaneous injections.

Two components of the package, that is the diary and medication colour-coding system, are worthy of special mention.

The diary proved to be of great value to both lay carers and visiting health professionals. Lay carers reported feeling a sense of security in having a record of injection administration as pressures associated with the caring role often led to an inability to accurately recollect medical detail. Many lay carers chose to continue using the diary even after the study period was completed. RNs and medical officers reported that they could easily interpret the information contained within the standard diary presentation and this helped them to monitor medication effectiveness, progress of symptom evolution and patient condition.

The colour-coding of medications was introduced as a safety measure to avoid medication errors, adapted from Australian and New Zealand Standard – *User-applied labels for use on syringes containing drugs used during anaesthesia*. [3] The colour-coded labels for pre-prepared syringes were rated highly by both lay carers and health professionals. Lay carers reported that they could easily distinguish between the different medications in the pre-prepared syringes enabling them to administer the right medication for the symptom, even when they were tired or distressed. For the RNs, the colour-coding system formed an easily identifiable basis to the medication education component of the framework. The colour-coded labels also proved time efficient for the RNs, as much of the information that needed to be written on each injection was pre-printed on the label templates.

The inclusion of a one-on-one teaching session for all lay carers to prepare subcutaneous injections was challenging to some health professionals. Initially, some RNs and service managers reported concerns about RN scope of practice and the legality of lay carers preparing and administrating subcutaneous medications. Indeed this concern has led to widespread national variability in home-based palliative care delivery. The 'Guidelines for the Handling of Medications in Community Based Palliative Care Services in Queensland' **(2)** was able to provide role clarity for RNs and lay carers related to the preparation and administration of subcutaneous medications in the home setting. It would be useful if similar guidelines were available to other states and territories across Australia.

For health professionals, an area of concern was whether lay carers could, or indeed should, fulfil the role expected of them for this project or whether the task of preparing and administering injections was too burdensome. The results from the RCT go some way to alleviating this concern. There were no significant differences in the confidence levels of lay carers irrespective of whether they or a health professional prepared injections. When well educated and resourced, lay carers are remarkably confident about preparing and administering injections for symptom control. Perhaps health professionals have been over-protective or have under-estimated the resilience and motivation of lay carers, when placed in the difficult situation of caring for a loved one at home.

The findings of this project are relevant to the newly drafted National Palliative Care Strategy, 2010 [(4)]; in particular to Goal 5 that aims to enhance the capacity and capability of all palliative care stakeholders. A well educated lay carer, who has 'on hand' access to dedicated information to support their ability to confidently manage symptoms with subcutaneous medications, is less likely to require additional support from their community-based healthcare providers. Similarly, a palliative patient who has access to timely administration of subcutaneous injections for symptom management is less likely to be inappropriately transferred to an in-patient setting. The benefits of this project for the patient, the lay carer and the healthcare system are self evident.

In conclusion, it is apparent that the resources developed by this project can augment lay carers' capacity and confidence to support palliative patients to be cared for in their environment of choice; in this case their home. These resources support the National Palliative Care Strategy aim of providing patient-centred care that delivers the right care, at the right time, in the right place.

2. MAIN PROJECT REPORT

2.1 Context

The National Palliative Care Strategy advocates a patient focused model of palliative care with emphasis on patient choice regarding the manner, setting and type of care that will allow them to live well at the end of life. [4, 5] A key element to realising this goal is the availability of a carer, whether it is a spouse, family member or friend, who is ready to provide care at home. Due to a lack of community resources, these relatives or friends are often called upon to adopt a quasi professional role involving interpreting medical signs and deciding which medications to use to improve symptom management. This can involve the use of subcutaneous injections.

Palliative care service providers understand the importance of the role of the lay carer in home-based palliative care; nonetheless evidence suggests that lay carers are provided with limited information, resources and supports to prepare them for such a role. [6,7,8,9] Having access to quality educational resources can enhance lay carers' knowledge and skill to safely and confidently prepare them to manage patients' subcutaneous medications. It can be expected that increasing the capacity of lay carers to manage symptoms will lead to a reduction of inappropriate presentations of palliative care patients to acute care hospitals.

2.2 Literature Review

Palliative care services strive to support palliative patients to be cared for within the setting of their choice with optimal symptom control and a pattern of care that is supportive of lay carers. [4, 5, 10, 11] Most palliative care patients wish to remain at home for as long as possible. Palliative patients are inherently unstable with respect to symptom emergence and when symptoms occur they require timely and appropriate responses. [6, 10, 12, 13] Palliative care professionals appreciate that the ability of patients to remain at home depends upon input from home-based carers, usually family members. As well as carrying out personal care, carers may also find themselves part of the symptom management team. This can require lay carers to interpret medical signs, deliver and adjust medication regimes as well as prepare and inject subcutaneous medications. [6, 13]

There is scant literature available concerning the practice of teaching lay carers of palliative patients to prepare medication(s) for subsequent subcutaneous administration. There appears to be resistance from some providers to teach lay carers the skills required to safely prepare and administer injections. Anecdotal evidence suggests that reasons for this resistance are due, in part, to organisational and individual uncertainty related to legal, jurisdictional and scope of practice issues for RNs and lay carers.

In terms of medication safety it has been suggested that a community-based pharmacist should be responsible for the preparation of subcutaneous medications that are used later in the home and, indeed, this is practiced in other countries. [14] This possibility has not been researched in Australia, presumably because the costs of such a practice would be prohibitive for health-care organisations and individuals.

Most literature concerning lay carers' ability to manage symptoms concentrates on their administration of pre-prepared syringes. [15, 16] A Brisbane based qualitative study by Israel et al [1] explored lay carers' perceptions in relation to their administration of subcutaneous medications for palliative patients. They found that while lay carers would not necessarily volunteer to administer subcutaneous medications, when bereaved they reported feeling empowered by the experience and satisfied that they had added value to their loved one's care. Conversely, lay carers reported feeling disempowered when they were unable to provide adequate symptom control.

There is ample literature to support the use of structured education programs, based on best-practice information, in achieving positive symptom control outcomes for patients and lay carers. [7, 9, 12, 16, 17, 18, 19, 20] Lay carers report the importance of education concerning all aspects of the administration of subcutaneous injections. [7, 8] Many felt that any resources they received from service providers were useful, but that they would have appreciated more targeted support. [1, 7, 8] In particular, lay carers frequently request information regarding medication management; advice on equipment required to prepare and deliver subcutaneous medications; and opportunities for supervised medication preparation and administration via a subcutaneous cannula. [8, 9, 16, 18, 19, 20]

Providing lay carers with the knowledge and skills to understand optimal symptom management assists them to have confidence to administer the right drug for the right symptom at the right time; [9, 12, 16, 17, 20, 21, 22, 23] however, an audit of palliative care services in South East Queensland [24] confirmed that there were no standardised educational packages available for lay carers administering subcutaneous injections.

Adult learning principles advocate that education should be multifaceted and inclusive of a variety of mediums. [18] The provision of education should be specific, as concise as possible and, most importantly, tailored to the needs of individual caregivers. [9, 16, 18, 19] Any education package established for lay carers of home-based palliative patients needs to be inclusive of these principles.

The primary intent of the CSAH project was to develop and evaluate a suite of educational resources able to be delivered in a standardised framework, to provide lay carers with consistent information that ensures they are competent to confidently manage subcutaneous medication administration in the home.

3. DELIVERABLES - KEY ACTIVITIES

3.1 Planning

Establishment of Steering Committee

A Steering Committee was established and first met in September 2007. This group met quarterly. Terms of reference were formulated and endorsed.

The purpose of the Steering Committee was to ensure ongoing governance and overall monitoring of the project and Working Group.

Members of the Steering Committee provided high level advice regarding strategies and operational requirements that facilitated the successful completion of the project.

Membership included:
- Blue Care
- Metro South Palliative Care Services (MSPCS)
- Centre for Palliative Care Research and Education (CPCRE)
- Consumer representative
- General Practitioner
- Karuna Hospice Service (KHS)
- St Vincent's Brisbane, Palliative Care Services (StVPCS)
- Palliative Care Physician (Sunshine Coast Palliative Care Services)
- Queensland Health (QH) Medicines & Pharmacy Services Unit
- QH Policy Branch
- Queensland Nurses Council

Establishment of Working Group

The purpose of the Working Group was twofold. Firstly, to provide clinical advice in relation to best-practice regarding subcutaneous medication administration. Secondly, to guide the development of a standardised educational framework, inclusive of all educational resources developed.

The Working Group was established and continued to meet regularly throughout the duration of the project.

Membership included representatives from:
- BSPCS
- CPCRE
- KHS
- StVPCS
- QH Safe Medicine Practice Unit (QH SMPU)

Invitations were extended to consumer representatives, domiciliary nursing services and other parties as required throughout the project.

Establish a Shared Vision

The vision was to enhance the capacity of lay carers to support palliative patients to remain in their home while receiving timely and optimal symptom control. In addition to supporting the desire of palliative patients to remain at home, the project aimed to ensure that their lay carers had the knowledge and skills to confidently and safely administer subcutaneous injections.

Recruitment of Project Staff

The recruitment process for a project coordinator was finalised in January 2008. The successful applicant remained in the position throughout the project.

In July 2009, a clinical nurse researcher was appointed three days per week to assist the project coordinator with the management of participants to ensure targets were achieved within the relatively short project timeframe.

3.2 Intervention - Development

Scoping Industry Practices

In November 2007, state and territory palliative care providers within Australia were surveyed by phone to explore current practices for their teaching of carers of palliative patients to prepare and administer breakthrough subcutaneous injections. [24] It was established that all states and territories, except Western Australia, provide one-on-one education to lay carers in relation to administration of breakthrough subcutaneous injections for symptom management in the home. Usual practice is that the RNs pre-prepare labelled syringes containing medication(s) that are then left in homes for lay carers to administer, as required, over the next 24 hour period. Silver Chain, the only home-care specialist palliative care service provider in Western Australia, offer a 24 hour home visiting service to administer breakthrough subcutaneous injections, so do not routinely teach lay carers to prepare and administer subcutaneous breakthrough injections.

In April 2008, the CSAH project conducted an audit of palliative care service providers across South East Queensland to determine if services providing palliative care had a 'dedicated educational framework' designed specifically for lay carers who are required to administer subcutaneous injections to palliative patients in the home. It was established that there was no dedicated standardised educational framework for lay carers. The majority of services provided education to the palliative care patient and their carers but provision was piecemeal. Locally produced resources included photographic material as well as printed information and instruction sheets.

Israel et al, [1] had identified gaps in education provision for lay carers in relation to the administration of subcutaneous injection(s) for palliative patients in the home. The study noted that educating lay carers can be time consuming and outlined a number of recommendations for the development of standardised educational resources that may more effectively assist lay carers in preparing and administering subcutaneous injections. These recommendations included such things as detailed information about prescribed palliative care medications; access to practical demonstration apparatus to gain familiarity with the equipment and processes associated with the preparation of injections, and standardised labelling systems for prepared breakthrough medications.

There is limited evidence available regarding the safety and shelf-life of pre-prepared subcutaneous medications stored in the home. It is routine practice for RNs to prepare the syringes and instruct lay carers to discard any medications not injected after 24-72 hours. A recent study conducted by the Royal District Nursing Service (RDNS) [25] in South Australia, represents some of the first evidence supporting the stability and sterility of medication(s) prepared in syringes in the home environment for subsequent use by a lay carer. Outcomes of that study suggest that some commonly used palliative care medications could be stored safely in syringes for up to seven days.

Scoping Legislative Requirements

At the commencement of this project, it was identified that many community based RNs were unclear on the legal, jurisdictional and scope of practice issues related to their common practice of preparing subcutaneous injections and leaving them for subsequent administration by the lay carer. Before the project could proceed it was necessary to resolve this issue. To aid with resolution, the BSPCC and the CSAH project coordinator, finalised the development of the 'Guidelines for the Handling of Medication in Community-Based Palliative Care Services in Queensland'. [2]

BSPCC progressed the endorsement of these guidelines. Endorsement was achieved from the Queensland Health (QH) Environmental Health Unit and QH Chief Health Officer in October 2008, and QH Patient Safety and Quality Executive Committee in August 2009.

These guidelines are compliant with the *Health (Drug & Poisons) Regulation 1996,* the *Guardianship and Administration Act 2000* and the *Powers of Attorney Act 1998;* and represent consensus-based best practice in palliative care. Recently the National Prescribing Service Limited (NPS) [26] acknowledged this document as a useful reference for identifying state-based guidelines that outline how medications should be managed within a community setting and recommended all states develop such documents.

These guidelines were pivotal to the successful implementation of this project.

Development of Educational Resources

Based on the work of Israel et al, a suite of resources was developed to support the standardised educational framework. (Refer Appendix 2) A team of palliative care clinical, academic and research professionals as well a consumer representative, informed the development of the resources which catered for different adult learning styles. Central to the framework is a time effective one-on-one educational session delivered by RNs to lay carers in the home setting. Mindful of the time required to teach lay carers and variability in adult learning styles, the resources were separated into mandatory and non-mandatory categories that could be delivered at the discretion of the RN and lay carer.

The resources, described below, were piloted and refined with input from lay carers and the Working Group prior to the commencement of the randomised controlled trial component of the project.

Mandatory Resources:

- **Illustrated step-by-step charts** that provide a simple guide for lay carers to follow, when required to prepare and administer subcutaneous injections. There are two options available when using this guide depending on the preference of individual services; a blunt needle or no needle technique. Option 1 'Preparing and Giving a Subcutaneous Injection 10 Step Plan – Using a Blunt Needle Technique' and Option 2 'Preparing and Giving a Subcutaneous Injection 10 Step Plan – No Needle Technique'.

- A **practice demonstration injection device** that includes a cannula inserted into stoma-type adhesive dressing that mimics a person's skin and other equipment involved with subcutaneous injections (eg. glass and plastic ampoules, blunt drawing-up needles and syringes).This device is useful for both the RN and the lay carer. The RN can use the device as a teaching aid during education sessions and the carer as a practice device after they have had the education.

- **Colour-coded medication labels** for labelling prepared syringes. The colour-coding system adopts the Australian and New Zealand Standard – *User-applied labels for use on syringes containing drugs used during anaesthesia.* [3] This allowed carers to easily distinguish between the different subcutaneous medications with the aim of reducing

carer stress and incidence of medication error. Labels must remain clear and legible. All injectable medications drawn up in syringes should be labelled IMMEDIATELY. The label is to be placed parallel to the long axis of the syringe and from the needle end of the syringe to the plunger.

- A **fridge magnet** consistent with the syringe label colour-coding system, allows the lay carer to match relevant medications with symptoms, ensuring the right medication is given for the right symptom. As pre-prepared syringes are stored in the fridge, this colour-coded guide for medications is placed on the fridge, providing another fail-safe to decrease the possibility of medication errors.

- A **daily diary** that allows lay carers to document aspects of medication administration, including date, time, medication type, reason for administration and symptom assessment score pre and post administration of medication, to measure its effectiveness. This allows the registered nurse and/or general practitioner to monitor the daily progress of symptom management.

- A **competency checklist** administered by the RN facilitating the education. This checklist provides the RN with a mechanism to confirm that competency to safely prepare and inject subcutaneous medications has been reached by the lay carer. This competency is a requirement under the *Health (Drugs and Poisons) Regulation* 1996.

Non-Mandatory Resources:

- A **medication booklet** 'Subcutaneous Medications and Palliative Care: A guide for caregivers'. This booklet covers topics such as frequently asked questions, importance of symptom control, management of common palliative symptoms, commonly used subcutaneous medications, and injecting processes. It also includes a brief overview addressing some of the common myths surrounding opioid usage.

- A **DVD** 'Palliative Subcutaneous Medication Administration: A guide for carers'. This 19 minute DVD, which can be viewed section by section or in entirety, demonstrates aspects of subcutaneous medication preparation and administration, safe storage and disposal of medications and includes a troubleshooting guide.

- Additional **illustrated step-by-step charts.** These one-page documents provide a simple guide for lay carers to follow when required to prepare and administer subcutaneous injections and cover the topics of 'Opening and Drawing Up from an Ampoule', and 'How to Give a Subcutaneous Injection via a Cannula' – Using a Blunt Needle Technique or Using a No Needle Technique.

- A **lanyard** was developed for RNs that included the colour-coded medication legend as well as the principles of the standardised education framework for easy reference.

Standardised Educational Framework

A framework was developed to standardise the delivery of education to lay carers. The framework facilitated the delivery of consistent information by the RNs across various health and geographical settings and incorporated flexibility for RNs to provide education to lay carers when they believed it was clinically indicated. (Refer Table 1)

To support RNs with the implementation of the standardised education package, they received on-site training in all aspects of the package prior to commencement of lay carer recruitment. A training manual was developed to ensure adherence to all aspects of the educational framework and to allow for future RN training by individual specialist and non-specialist palliative care services.

Table 1: Elements of Standardised Educational Framework

Focus	Rationale	Framework Element
1. Routinely teach lay carers to prepare injections for subcutaneous use	▪ Palliative patients are inherently unstable and require timely access to palliative medications as soon as symptoms emerge ▪ At times lay carers may run out of pre-prepared medication and therefore should have the skills to prepare an extra injection, to ensure timely access to palliative medication(s) for symptom control	▪ RNs across all pilot sites were asked to teach lay carers to prepare subcutaneous medications at a clinically appropriate time ▪ RNs support lay carers throughout this process
2. Competency of lay carers to prepare and administer subcutaneous injections	▪ RNs have a legal obligation to ensure that a lay carer taught to prepare and administer a subcutaneous injection(s), is competent to do so ▪ Lay carers must be provided with appropriate training to safely assist with medication administration	▪ A simple competency checklist was developed for RNs to confirm lay carer's competency
3. Use of blunt needle or no needle technique	▪ Best-practice to maximise patient/lay carer and staff safety, to reduce the incidence of needle stick injury.	▪ Provide advice on best-practice principles related to the use of non-sharp or a needle-less system as part of standardised practice
4. Patency of subcutaneous access	▪ To ensure palliative patients have patent subcutaneous access for medication(s) administration ▪ The insertion of a second saf-t-intima guarantees timely access to subcutaneous medications. (This practice is only followed by some specialist palliative care service providers) ▪ A likely consequence of lay carers unable to access subcutaneous sites is inappropriate presentation to an emergency department. This represents a potentially poor outcome for the patient, the carer and the health system.	▪ To insert a second saf-t-intima when the need to provide subcutaneous injections is identified becomes standard practice.
5. Delivery of the complete dose of subcutaneous medication	▪ Some subcutaneous medication doses are delivered in very small volumes, therefore flushing ensures the palliative patient receives the complete dose of prescribed medications	▪ RNs to teach carers to flush the saf-t-intima with a minimum of 0.3mls - 0.5mls of normal saline after each breakthrough injection

3.3 Intervention - Methodology

Ethics Approval

The project was approved by the following Human Research Ethics Committees (HREC):
- Princess Alexandra Hospital Queensland Health
- St Vincent's & Holy Spirit Health Services
- Blue Care
- Cittamani Hospice Service
- Karuna Hospice Service Boards
- Spiritus

Design

The first component of this project was to develop and implement a standardised educational and support package concerning the administration of subcutaneous medications. This package was then trialled across urban, regional and rural settings and evaluated, quantitatively and qualitatively, using lay carer and RN responses to semi-structured questionnaires covering content, efficacy, safety and satisfaction domains.

The second component was to conduct a randomised controlled trial to identify possible differences in outcomes for lay carers in terms of confidence when assessed across the three following conditions:

i Carer prepares, labels and stores daily breakthrough medications for subsequent injection
ii RN prepares and labels daily breakthrough medications for carer to store for subsequent injection
iii Clinical Trial Pharmacist prepares and labels daily breakthrough medications for carer to store for subsequent injection.

Sample

Two participant groups were identified and evaluated.

The first group were lay carers who had received the standardised education and resource support package and who may subsequently be required to deliver subcutaneous injections to palliative patients for symptom control in the home setting.

The second group were RNs from specialist and non-specialist palliative care services who had provided the standardised education to lay carers.

Research Instruments, Statistics and Study Flow

Lay Carer Questionnaires and Diary

Two semi-structured questionnaires were developed for lay carers. The first questionnaire was completed immediately following the delivery of the standardised education package. The second was completed four weeks after completion of the study, i.e. four weeks after the lay carers had completed diary entries for a maximum of 14 days.

The first questionnaire aimed at rating the usefulness of the education and resources provided, as well as carers' perceptions of confidence, safety, efficacy, satisfaction, and stress levels with regard to their future delivery of subcutaneous medications. The first section of the questionnaire asked for global ratings of the education package in terms of relevance to needs, ease of understanding, potential helpfulness in reducing stress, medication administration and satisfaction with the information provided with regards to the probable need for the lay carer to administer subcutaneous injections to the palliative patient at home.

The second section asked lay carers whether they felt that the education package had increased their confidence for preparing, labelling and administering injections, managing the injection site and symptoms, and understanding the use of common palliative care medications.

The potential usefulness of specific aspects of the education package was evaluated in the final section. Aspects evaluated included the face-to-face education session, the written and illustrated information provided in the packages, the demonstration and supervision while giving a subcutaneous injection, and the DVD included in each package.

The second questionnaire was similar to the first except that it contained additional components that asked lay carers to rank the usefulness of resources actually used after they had experienced injecting.

All questions were answered on 7-point Likert type rating scales where a higher score indicates a more positive response. Interpretation of the mean ratings and 95% confidence interval (CI) were based on a mean higher than 5, indicating a very positive response on average, and the lower limit of the 95% CI above 4, indicating consistent agreement amongst respondents about the high rating.

The Randomised Controlled Trial (RCT)

After the completion of the education session in which all lay carers were shown how to prepare and administer injections, carers were quasi-randomly allocated to one of three intervention groups: 1) lay carer draws up and prepares the injection 2) RN prepares the injection or 3) pharmacist prepares the injection. Allocation was quasi-random because only lay carers who lived within the catchment area of the project pharmacy could be allocated to that condition.

Lay carers were asked to complete a daily diary for a maximum of 14 days after they had begun injecting. Entries included the medication name, dose and frequency given and the effect the injection had on the symptom. The lay carer was asked to rate their level of confidence after each injection administered using a 7-point Likert type scale with endpoints, not at all confident, 1 and extremely confident, 7.

The question of interest for the RCT was whether there was a difference in overall confidence when the lay carer was responsible for preparing the injections, compared to when another person (the RN or pharmacist) was responsible for preparing, which can be tested using an independent samples t-test. A difference of one point on the 7-point Likert type confidence rating scale could be regarded as clinically significant. The overall ratio of participants in the other condition to the self-condition was planned to be 5:3. At the 5% confidence level, and assuming the standard deviation of the confidence rating to be 1.25, the study would have power of 80% to detect a difference in one point in overall confidence with a total sample size of 56 participants in a two sided independent samples t-test.

Given the proposed sample size of 56 participants for the trial component of the study, this would provide sufficient power for very precise estimates of carer evaluations of the educational package; mean (95% confidence interval) plus/minus 0.32 points.

RN Questionnaire

A semi-structured questionnaire was developed and completed voluntarily at the conclusion of the study, by all RNs who had delivered the education package. The questionnaire aimed to evaluate the standardised educational package across content, efficacy, safety, and satisfaction domains. It was based on a 7-point Likert type scale with endpoints, strongly disagree, 1 and strongly agree, 7.

The first section of the RN questionnaire asked for ratings concerning overall aspects of the package, including ease of delivery, quality of resources and appropriateness to the needs of lay carers. The second section, asked RNs how well they thought the various issues had been explained, on a scale from poorly explained, 1, to well explained, 7. The third section asked RNs to rate the usefulness for lay carers of the resources within the education package, from not at all useful, 1, to extremely useful, 7.

RN Focus Groups

At the completion of the study, focus groups were held with a purposive sample of specialist and non-specialist palliative care RNs from participating pilot sites. The interview questions were informed by findings from the RN questionnaire. The purpose of the focus group was to explore post hoc any issues that had arisen with the implementation of the study.

Data collection

An Excel spreadsheet was developed to facilitate statistical analysis using Statistical Package for the Social Sciences (SPSS) in consultation with the statistician. Throughout the trial the systems and processes for data collection and management were constantly monitored and adapted to ensure data integrity.

Recruitment

Lay Carers

Potential lay carers were initially identified by clinical RNs. Lay carers were subsequently contacted by a member of the research team to discuss the trial and obtain consent.

Specialist and Non-Specialist Palliative Care Service Providers

A total of 24 trial sites situated in urban, regional and rural areas of South East Queensland were recruited. Of the 24 sites, 7 were specialist palliative care services and 17 were non-specialist palliative care services. (Refer Table 2)

Clinical Trial Pharmacist

In January 2009, a pharmacist from Wesley Hospital in Brisbane was engaged to prepare and label daily subcutaneous breakthrough medications for delivery to lay carers randomly allocated to the pharmacy arm.

Table 2: Pilot sites

Urban	Regional	Rural
Metro South Palliative Care Services – Princess Alexandra Hospital – Canossa Hospital – Brisbane South Community Health (CH) – Bayside (CH) – Logan (CH)	**Metro South Palliative Care Services** – *Logan (CH)	**Metro South Palliative Care Services** – *Logan (CH)
Blue Care – Brisbane South – Brisbane North – Springwood – Beenleigh – Wynnum	**Blue Care**: – Redlands – Caloundra – Toowoomba – Beaudesert	**Blue Care** – Crows Nest – Boonah
Spiritus – Brisbane South – South East – Brisbane North – Zillmere – Bayside – Logan	**Spiritus** – *Logan	
St Vincent's Palliative Care Service, Brisbane	***Cittamani Hospice Service**	***Cittamani Hospice Service**
Karuna Hospice Service	***Karuna Hospice Service**	

* Indicates services that cover both regional and/or rural geographical areas

4. EVALUATION

Results

Recruitment to the study commenced in February 2009 and ceased in January 2010. In this period the project team flagged 347 potential lay carers of which 169 were approached. Of the 169 lay carers approached, 165 consented to participate, 106 were randomised to the RCT and 94 lay carers completed the RCT. These numbers were in excess of projected requirements in terms of power, but given the benefits to carers of participation in the study, and benefits of increased statistical power with larger sample size, the project team decided to recruit as many participants as possible.

Often in palliative care research it is difficult to accrue sufficient numbers to a trial. It was surprising that in this instance recruitment went so successfully, reflecting the acknowledgement by both lay carers and palliative care health workers of the advantages of learning the skills that would be of practical importance to the carers in keeping their loved ones at home.

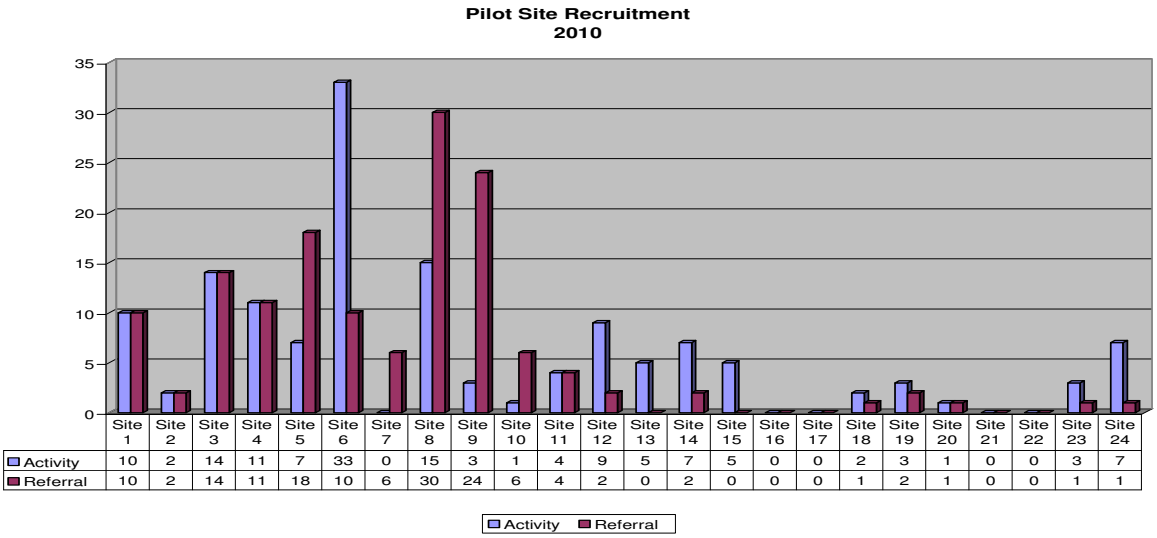
Furthermore, it was of interest to carry out pairwise comparisons between all conditions of the RCT – injections prepared by carer, RN and pharmacist – and the larger sample sizes made this possible. The average length of stay for participants on the RCT component of the project was 8.2 days.

Participant profile

The majority of project participants were female 74% (123), spouses, partners or daughters, with a relatively even distribution of ages. Lay carers' ages ranged from 18 to 76 years and over. The majority of lay carers 49% (82) were aged between 46-65, 31% (51) were aged between 18-45 and 19% (22) were 66 or over; 4% (7) were over 76 years. In terms of geographical distribution, 81% of participants were recruited from urban areas, with smaller percentages from regional 16% and rural populations 3%.

Of the 165 lay carers that consented to participate, 106 were randomised to the RCT and 94 lay carers completed the RCT. Of the 94 lay cares that completed the RCT, 34 were randomised to the carer group; 35 were randomised to the registered nurses group and 37 to the pharmacy group. Graph 1 outlines the pilot site recruitment for the duration of the project. Sites were de-identified and assigned a unique number.

Graph 1: *Pilot Site Recruitment*



	Site 1	Site 2	Site 3	Site 4	Site 5	Site 6	Site 7	Site 8	Site 9	Site 10	Site 11	Site 12	Site 13	Site 14	Site 15	Site 16	Site 17	Site 18	Site 19	Site 20	Site 21	Site 22	Site 23	Site 24
Activity	10	2	14	11	7	33	0	15	3	1	4	9	5	7	5	0	0	2	3	1	0	0	3	7
Referral	10	2	14	11	18	10	6	30	24	6	4	2	0	2	0	0	0	1	2	1	0	0	1	1

Evaluation of the Education Package by Lay Carers

Questionnaires were returned by 76 lay carers at *Time 1* after the face-to-face education session, and 62 lay carers at *Time 2*, after experience with administering subcutaneous injections in the home. Mean ratings and 95% confidence intervals for these lay carers are shown in Table 3.

Global satisfaction with the education package was rated highly. Across both *Times 1* and *2*, means were greater than 6 out of a maximum of 7, indicating a high level of satisfaction both before and after the relevant experience of administering injection(s).

In terms of lay carers' confidence with subcutaneous injection management, means were uniformly high at both times, indicating the benefits of the education package in preparing lay carers for the task of administering injections.

The potential usefulness of specific aspects of the education package were evaluated in the final sections of the questionnaires. Aspects evaluated included the face-to-face education session, the written and illustrated information provided in the packages, the demonstration and supervision while giving a subcutaneous injection, and the DVD included in each package. Rated usefulness was high for all aspects as shown in Table 3.

Overall, the education package was rated highly by lay carers, both when assessed immediately after the face-to-face education session, and after experience with administering subcutaneous medications. The results show that the lay carers' responses means were all equal to or above 5.9, indicating that lay carers found the package to be useful in enabling them to deal confidently with symptoms arising in the palliative patient at home. See Appendix 3 lay carer questionnaire comments at *Time 1 and 2*.

In summary, the package was perceived by lay carers as being beneficial in terms of subcutaneous medication management. Having access to quality information was associated with a reduction in lay carer stress and increased level of lay carer confidence with subcutaneous injection administration. Lay carers reported that the colour-coded system assisted them in administering the right drug for the right symptom.

Table 3: Lay carer evaluation of the education package immediately after the face-to-face session (*Time 1*) and four weeks after trial completion (*Time 2*)

	Time 1		*Time 2*	
	Mean	**95% CI**	**Mean**	**95% CI**
Global evaluation of the education package				
1. Relevant to needs	6.5	6.4-6.7	6.5	6.4-6.7
2. Easy to understand	6.4	6.3-6.6	6.3	6.1-6.6
3. Help to reduce stress	6.3	6.1-6.5	6.1	5.8-6.4
4. Give necessary skills	6.5	6.3-6.6	6.1	5.8-6.4
5. Satisfaction with information	6.5	6.4-6.7	6.3	6.0-6.6
Increase in confidence				
6. Prepare and label injections	6.2	6.0-6.4	5.9	5.5-6.4
7. Safely inject	6.4	6.2-6.5	6.4	6.1-6.6
8. Safely manage injection site	6.2	6.0-6.4	6.3	6.0-6.6
9. Manage symptoms	5.9	5.6-6.1	5.9	5.6-6.2
10. Understand common palliative care medications	6.0	5.8-6.3	6.2	5.9-6.5
Specific aspects of the education package				
11. Face-to-face session	6.7	6.6-6.8	6.6	6.4-6.8
12. Pictorial charts	6.3	6.0-6.5	6.4	6.1-6.6
13. Colour-coded labels	6.6	6.5-6.7	6.5	6.2-6.7
14. Fridge magnet	6.2	6.0-6.5	6.2	5.8-6.5
15. Daily diary	6.4	6.3-6.6	6.5	6.2-6.7
16. Competency checklist	6.0	5.7-6.3	5.9	5.5-6.3
17. Guide booklet	6.2	5.9-6.5	6.4	6.1-6.7
18. Practical demonstration by nurse	6.7	6.6-6.8	6.8	6.7-6.9
19. Using demonstration kit	6.6	6.5-6.8	6.5	6.3-6.7
20. Supervised injection into cannula	6.6	6.4-6.8	6.7	6.5-6.9
21. DVD on subcutaneous medication administration	6.1	5.9-6.4	6.1	5.5-6.8

Evaluation of the Education Package by RNs

A total of 217 RNs from 24 trial sites were trained on how to deliver the standardised education, though not all of these RNs subsequently delivered the education. Of those who did deliver education, 53 returned questionnaires.

RNs rated the education package highly in terms of overall aspects such as appropriateness to the needs of lay carers, and providing the necessary information to allow lay carers to safely prepare and administer subcutaneous injections. Similarly they indicated that the issues relevant to subcutaneous injections of palliative care medications had been well explained, and that the components of the education package provided useful resources for lay carers. Specific items, together with means and 95% CI are shown in Table 4. See also Appendix 4 health professional questionnaire comments.

Table 4: Evaluation of education package by registered nurses

	Mean	95% CI
Global evaluation of education package		
1. Easy to deliver	5.2	4.9-5.5
2. Opportunity to assess carer competence related to subcutaneous injections	5.5	5.2-5.7
3. Provides framework for consistency in carer education	5.6	5.4-5.9
4. Appropriate to carer needs	5.6	5.3-5.9
5. Provides quality resources	5.9	5.6-6.2
6. Provides necessary information for safe preparation	5.8	5.5-6.0
7. Provides necessary information for safe administration	5.9	5.7-6.1
8. Sufficient practice material in demonstration kit	5.7	5.4-6.0
9. Recommend continued use	5.5	5.1-5.9
Adequacy of explanation of issues		
10. Safe preparation and labelling of subcutaneous injections	5.6	5.3-6.0
11. Safely injecting	5.8	5.5-6.0
12. Safely managing the injection site	5.8	5.5-6.0
13. Managing symptoms	5.4	5.1-5.7
14. Understanding commonly used palliative care medications	5.4	5.0-5.8
Usefulness of specific aspects of the education package		
15. Face to face education session	6.0	5.8-6.2
16. Pictorial charts	6.0	5.7-6.3
17. Colour-coded labels	6.2	5.9-6.5
18. Fridge magnets	5.3	4.8-5.8
19. Diary	5.8	5.5-6.1
20. Competency check list	5.6	5.2-6.0
21. Demonstration kit	6.1	5.8-6.3
22. DVD	5.4	5.0-5.7
23. Booklet	5.8	5.5-6.1

RN Focus Group

Focus groups were held with a purposive sample of 26 RNs from specialist and non-specialist palliative care services following the completion of the project. A question of particular interest was 'When is the right time in the palliative patient's trajectory to deliver lay carer education regarding subcutaneous medication administration?' General consensus from RNs was that there is 'no right time' and that the timing to deliver the education is dependant on individual lay carers.

RCT: Lay Carer Confidence in Administration of Injections According to Who Prepared the Injections

The RCT explored whether lay carer confidence differed according to who prepared the medication(s) for subsequent injection.

Data to measure lay carer confidence was gathered from daily diary entries completed by lay carers at the time each injection was administered. A total of 1429 daily diary sheets were returned by 94 lay carers. Of these, 123 were discarded as someone other than the lay carer (i.e. a health professional) had administered the injection. Administration of injections was tracked for a maximum of two weeks after the face-to-face education session. The actual number of days over which lay carers injected ranged from 1 to 15, with the total number of injections per carer ranging from 1 to 68. Of interest, an audit of the 1306 injections administered by carers revealed that all injections given contained medications that were appropriate to the symptom reported.

It was postulated that lay carers may be less confident if they had the responsibility of preparing the injection as well as administering it. Analysis of variance indicated that there were no significant differences between groups in level of confidence in their administration of the injection, $F(2,92) = 0.50$, $p=.60$, and inspection of the means for level of confidence, ranging from 5.91 to 6.09 across groups, support this lack of significant difference.

Information related to the injections administered by lay carers within each condition is shown in Table 5.

Table 5: Information related to the injections administered by lay carers with each intervention condition

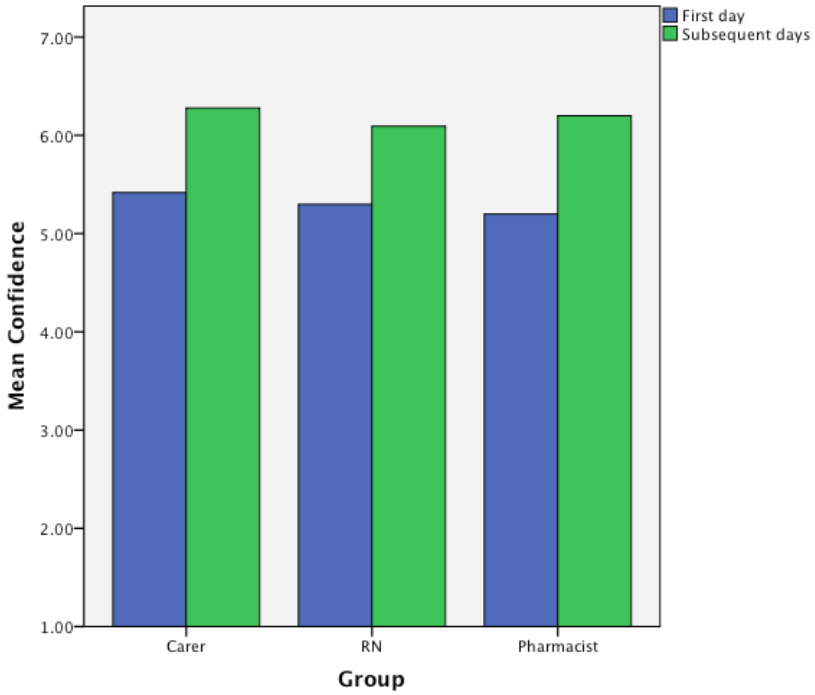
Group (responsibility for injection preparation)	N	Mean number of days tracked (range)	Mean number of injections administered by carer (range)	Mean level of confidence in injection administration (range)
1. Carer	27	7.67 (1-15)	14.63 (1-49)	6.09 (3.8-7.0)
2. RN	31	5.87 (1-14)	15.48 (1-66)	5.91 (4.5-7.0)
3. Pharmacist	36	4.83 (1-14)	11.97 (1-68)	6.04 (4.5-7.0)
Total sample	**94**	**5.99 (1-15)**	**13.89 (1-68)**	**6.01 (3.8-7.0)**

It might be argued that the lay carers' confidence could be higher because they had more days of experience injecting over the course of the study. However, when number of days or number of injections was controlled for by entering it as a covariate into the analysis, the absence of differences between means did not change.

To eliminate the possibility that the confidence level of lay carers may have developed after the first injection from an initial lower level, group changes in confidence ratings from the first day of injections administered to later days were examined in a split-plot analysis of variance. For the lay carer group, 14 carers provided relevant data, and mean confidence on the first day of injecting was 5.42 (SD = 1.11), for the RN group mean confidence was 5.30 (SD = 1.28, N=19)

and for the pharmacist group mean confidence was 5.20 (SD = 1.18, N=21). For subsequent days of injections, the means for lay carers were 6.28 (SD = 0.69), 6.09 (SD = 0.58) for those in the RN group, and 6.20 (SD = 0.68) for the pharmacist group. The increase in confidence with experience of administering injections, from 5.3 (SD = 1.18) on the first day to 6.2 (SD = 0.65) on subsequent days, averaged over groups, is statistically significant, $F(1,68) = 50.6$, $p<.01$. However, neither the mean level of confidence nor the change in confidence differed significantly across groups. (Refer Figure 2)

Figure 2: Group changes in confidence from first to subsequent day's injections experience



In summary the RCT found that lay carers can confidently and safely manage subcutaneous medications, regardless of whether the lay carer, RN or Pharmacist prepares the injections. Furthermore, confidence with injecting improves significantly with experience. Appendix 5 provides an overview of participant flow through the clinical trial.

5. DISCUSSION

Results from the CSAH project demonstrate that, if lay carers are supported with quality resources and standardised information, they can confidently, competently and safely manage symptoms that require the delivery of subcutaneous medications to home-based palliative care patients. Further, lay carers' confidence with symptom management is not diminished when they, rather than a health professional, such as an RN or pharmacist, prepare the injection. Not surprisingly, when lay carers are well educated regarding symptom management, their levels of confidence increase as they gain experience with preparing and administering subcutaneous injections.

It is likely that these findings can be translated into fewer inappropriate presentations of home-based palliative care patients to acute care hospitals, as well as less demands on palliative care services to manage symptoms. Consequently, these findings are likely to have positive impacts for lay carers, home-based palliative patients, palliative care services and the Australian healthcare systems.

The CSAH Educational and Resource Package encourages the provision of consistent information to lay carers by providing specialist and non-specialist palliative care providers with standardised educational resources. This is important as the Palliative Care Australia model of palliative care service provision [27] advocates a shared care approach, where often both specialists and non-specialists input into home-based care. If professionals on either individual or organisational levels are being inconsistent in their information giving, then lay carers can become bewildered and distressed. A consistent standardised approach avoids poor lay carer and patient outcomes. While the resources developed in this project are standardised, they are nonetheless, flexible enough to cater for individual learning styles.

Two of the components of the package, that is, the diary and medication colour-coding system, are worthy of special mention.

The diary provided to lay carers encouraged them to record every injection given, as well as noting the effectiveness of that medication for symptom relief. This clinical tool proved to be of great value to both lay carers and visiting health professionals. Lay carers reported feeling a sense of security in having a record of injection administration, as pressures associated with the caring role often led to an inability to accurately recollect medical detail. Many lay carers chose to continue using the diary even after the study period was completed. RNs and medical officers reported that they could easily interpret the information contained within the standard diary presentation and this helped them to monitor medication effectiveness, progress of symptom evolution and patient condition.

The colour-coding of medications was introduced as a safety measure to avoid medication errors. The colour-coded labels for pre-prepared syringes were rated highly by both lay carers and healthcare professionals. Lay carers reported that they could easily distinguish between the different medications in the pre-prepared syringes, enabling them to administer the right medication for the symptom, even when they were tired or distressed. Injections were always stored in a secure container in the refrigerator. The fridge magnet incorporated the colour-coding system and provided another visual prompt for the lay carer. The magnets were designed to be written on, so changes in medication could be easily up-dated by RNs or lay carers. For the lay carers, contemporaneous information on the fridge magnets and syringes improved knowledge and understanding of the medications being administered, which could then be cross referenced with information from the other resources, such as the booklet or DVD. For the RNs, the colour-coding system formed an easily identifiable basis to the medication education component of the framework. The colour-coded labels also proved time efficient for the RNs as much of the information that needed to be written on each injection was pre-printed on the label templates.

During the course of this project the QH SMPU became involved in a National Labelling Project (NLP). [28] The NLP aims to assist health professionals to identify correct medications and the correct route of administration for injectable medications through the use of labelling. The labels are currently being piloted in hospitals and will soon become mandatory for use in all hospital settings across all jurisdictions. Results from the CSAH project have been of interest to the NLP, as they relate to the community setting. To ensure future standardisation across the hospital and community interface, modifications to the existing label design utilised in the CSAH project have now been incorporated.

The inclusion of a one-on-one teaching session for all lay carers to prepare subcutaneous injections was challenging to some health professionals. However, having this skill ensured that lay carers were always in a position to contribute to timely symptom control. Initially, some RNs and service managers reported concerns about RN scope of practice and the legality of lay carers preparing and administrating subcutaneous medications. Indeed this concern has led to widespread national variability in home-based palliative care delivery. The 'Guidelines for the Handling of Medications in Community-Based Palliative Care Services in Queensland' [2] was able to provide role clarity for RNs and lay carers related to the preparation and administration of subcutaneous medications in the home setting. It would be useful if similar guidelines were available to other states and territories across Australia.

Furthermore, a particular area of concern for health professionals was whether lay carers could, or indeed should, fulfil the role expected of them for this project or whether the task of preparing and administering injections was too burdensome. The results from the RCT go some way to alleviating this concern. There were no significant differences in the confidence levels of lay carers irrespective of whether they or a health professional prepared injections. When well educated and resourced, lay carers are remarkably confident about preparing and administering injections for symptom control. Perhaps health professionals have been over protective or have under estimated the resilience and motivation of lay carers when placed in the difficult situation of caring for a loved one at home. However, it should be noted that for this study it was the clinical RNs who initially recommended lay carers to the research staff; perhaps they only referred psychologically robust individuals?

The findings of this project are relevant to the newly drafted National Palliative Care Strategy, 2010 [4], in particular to Goal 5 that aims to enhance the capacity and capability of all palliative care stakeholders. A well educated lay carer, who has 'on hand' access to dedicated information to support their ability to confidently manage symptoms with subcutaneous medications, is less likely to require additional support from their community-based healthcare providers. Similarly, a palliative patient who has access to timely administration of subcutaneous injections for symptom management is less likely to be inappropriately transferred to an in-patient setting. The benefits of this project for the patient, the lay carer and the healthcare system are self evident.

6. RECOMMENDATIONS

The following recommendations were endorsed by the CSAH Steering Committee for future consideration by the Department of Health and Ageing:

1. Development of a Train-the-Trainer Manual for the implementation of the Standardised Educational Framework to all relevant service providers across Queensland with a view to a national implementation.

2. Modification of the suite of educational resources in a format that is accessible electronically. Resources could be posted on websites for ease of access, particularly for rural and remote palliative care providers. Suggested websites include but are not limited to CareSearch; Carers Australia; QH Safe Medication Practice Unit; state-based and national peak palliative care bodies and individual service provider intranets.

3. Reprinting of all resources for distribution to relevant Queensland stakeholders.

4. Exploration of the possible use of these resources for carers in other settings where end of life care is delivered with limited access to registered nursing staff eg. hostel style supported accommodation.

7. CONCLUSION

A palliative patient's preference to be cared for at home or for a home death is usually reliant upon a lay carer being able to confidently and appropriately provide symptom relief. Such provision can require subcutaneous medication management.

The CSAH project developed, implemented and evaluated a standardised education and resource package that allows lay carers to confidently and safely prepare and administer subcutaneous medications to those who need them. The package has been rated highly by lay carers and RNs. The RCT associated with the CSAH project indicates that lay carers' confidence in delivery of subcutaneous injections is not dependant upon who prepares the injections and also that lay carers' confidence with injecting increases as they have more experience.

The resources developed by this project can augment lay carers' capacity and confidence to support palliative patients to be cared for in their environment of choice; in this case their home.

These resources support the National Palliative Care Strategy aim of providing patient-centred care that delivers the right care, at the right time, in the right place.

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9. Appendices

Appendix 1: Guidelines for the Handling of Medication in Community-Based Palliative Care Services in Queensland

Appendix 2: Standardised Education and Resource Package

Appendix 3: Lay Caregiver Questionnaire 1 & 2 Comments

Appendix 4: Health Professional Questionnaire Comments

Appendix 5: Randomised Controlled Trial Flow Chart

Appendix 1

Guidelines for the Handling of Medication in Community Based Palliative Care Services in Queensland
2009

Appendix 2

Caring Safely at Home Updated Standardised Education and Resource Package

Appendix 3

Questionnaire 1 (Time 1) – Collated summary of lay caregiver's comments

Questionnaire 1 - Comments
Didn't have time to watch DVD. Labels far to large for syringes. What do you do with all the paper? Get in the way. Someone ringing after a really tough emotional day asking if I have filled in this form. Not on! Information should have been gone through before the day we started. The whole thing was overwhelming. To much information / when you are dealing with a new level of patient care. Nurse was wonderful.
Labels to large
I didn't get a chance to view the DVD or read the booklet thoroughly but having the materials available to use was comforting. I found the step by step chart of immense value and support.
I feel it would be useful to separate the training from the nursing care experience. In our situation the training was given after the RN had provided the usual hygiene care of our mum and I think it would have worked better to be shown at a different visit.
This package is very helpful to me as I have not done this before. The help the team gave me, was of great assistance.
Felt very confident giving my mother pain relief when required and being able to relieve stress and discomfort also good support from Palliative Care Team which gives me more confidence to be able to help my mother at home. [redacted]
I have 30 years experience in F/training, volunteer with [redacted], over the years has made me confidence in preparing for a situation like this. Both my parents had cancer and the knowledge of looking after them has prepared me to do this same for my husband.
The pictorial charts are confusing because some steps were duplicated and overlapped - not clear which one to follow. Had some problems injecting into the cannular initially. The instruction provided by [redacted] was excellent.
Add to DVD eg what to do if blood in tube - seeing this is a common occurrence
Once I had become fully acquainted with my extended duties I concluded that as a novice I would be able to cope with the 'caregivers' package due to the exacting nature of the process and given the great amount of stress and tiredness I'm trying to cope with I am unable to continue. However with the [redacted] drawing up the medication I am very comfortable with giving the breakthrough medications.
I felt very apprehensive about giving my mother subcutaneous injections before [redacted] demonstration. After the demo, I felt as though I was ready to do whatever I possible could to help relieve my mother from pain, nausea, restlessness or whatever! The outcome after the injections was well worthwhile. Thank you for making this wonderful experience possible, especially being able to do so in our own home where family and friends are welcome. C.2.1 Pictorial charts - haven't had to draw up our own ampoules. C.2.2 Colour coded ampoules - excellent for identifying at a glance. C.2.4 Daily Diary - good to know exactly when, why and outcome of giving particular injections. C.2.5 Competency check list - ? did one of the nurses fill this out. C.2.6 Booklet - very helpful to have and refer to. C.3.3 Practical demo - gave me confidence. C.3.2 Using demo kit - pleased to be able to practice first.
Practical demonstration was most beneficial to me particularly given that I did not have much spare time to read all the written material that was provided.

Questionnaire 1 - Comments
I prefer the abbreviated info (ie the single sheet) rather than the whole booklet (which I glanced at once). The hand-on instruction was of the most benefit. The info sheet helped as a back-up. I can not stress enough the importance of the face to face training/support. The actual practice kit was of some use but the printed material served only as a back-up. An extra consideration may also be post death support. I think myself quite balanced and sane (some may disagree) but even so am having thoughts of how my giving drugs affected Dad at the end. I think this is probably normal and I am handling things ok but others may not...
Actually giving the injection immediately after the education and under supervision was the best means to developing the skill and my confidence. While we fell under the pharmacy trial (group) I felt that, if needed, I would feel reasonably confident to prepare and label the syringes /medication. While the various medications (and number of them) were a little confusing at first, the colour coding system was extremely helpful as was the fridge magnet and especially the book included in the package, especially regarding possible side effects. This was more applicable to the education provider (nurse)? Not only was the book extremely useful to us, I felt it was a useful resource in reinforcing information received from nurses, to relay to other family members/caregivers in the house who may have been conflicted about us giving injections (drugs). This book could assist in allaying some of these concerns. I can attribute my confidence in administering the injection on the 3rd occasion, unsupervised, to the supervision and advice given on this first 2 occasions. (especially as the patient experienced some pain which made me hesitant the 2nd time).
I found [redacted] demonstration extremely helpful. It gave me the confidence to give the injections initially. I now feel that this 2 weeks of using drawn-up injections has given me the confidence to go to the next step of drawing up on my own. This whole experience is wonderful - to be able to care for a loved one in the home environment and know that you are responsible and able to contribute to them being pain free. Thank you. C.2.1 Pictorial charts - Haven't needed to use these. I consider these will be useful if we have to draw up the drugs. C.2.5 Competency check list - ? Is this for the demonstrator to fill out? C.2.6 Booklet - may be more helpful as time goes on
I haven't rated these (the education package) more highly because - although your package is very good, I feel that the explanation and hands on session with the nurse gave me the most info and confidence. I'm a hands on learning person. Manage symptoms - depends on how bad the symptoms become - sometimes will need medical guidance (by phone?) to know what to inject and how much. If you are panicking or worrying about severe symptoms, the best package in the world won't help. You need verbal reassurance and communication. Fridge magnet - put it on the fridge but didn't need it [redacted] was in his last days and was being managed by [redacted] and GP. Fridge magnet and booklet necessary but we were under the direction of [redacted] and our GP and we made notes to follow according to their directions. Competency check list - covered by nurse's talk. DVD - didn't look at it - felt that after the above, we felt competent. Some people would need it no doubt. It was an absolute privilege to care for my husband at home - an amazing, difficult, beautiful and sad time. How wonderful that he died at home with me beside him. Sorry I've left this so late. It was impossible to do this questionnaire "as soon as possible after receiving the education". - no time - not in any emotional or physical state to fill in a questionnaire when you are a full time carer and your "patient" is in his final days.
My experiences were very positive. My first injection was a bit scary as the demo box has two points available but when on the person there is only one. Maybe having the extra tubing which would go to the driver might help. The colour coding for the medication was excellent but at times trying to match the medication to the symptoms was a little tricky as Dad couldn't speak. Maybe a little more medication information could help. Overall it is an excellent to be able to help Dad relieve any pain or stress. All the staff we dealt with were amazing. Keep up the outstanding carer's help.

Questionnaire 1 - Comments
I really want to become more confident in caring for my husband [redacted] in these last precious days together - and am so grateful for all this help and support. It has been a real learning experience these past 5 years. Maybe what I have learned will help someone else going through it - one day - because there is really need to feel 'alone'.
The education package allowed me to care for family at home. Also I managed this with the help and advice from the [redacted]. Family member passed away peacefully, happy to be at home with family, not among strangers in hospital. Thank you for allowing me to participate it was very useful.
I found the information very helpful and useful for anything that cames up in future. I suppose I feel much more confident than before to deal with [redacted] illness.
Did not see DVD. I did not get a chance to see the DVD because the kit wasn't opened until 22/04/09, perhaps the booklet and DVD could be given to the carer earlier at the face to face session separately when the carer has a bit more time before things start to get hectic. The nurses from [redacted] had not seen the kit before - maybe the kit should be available to all hospice Services.
I feel very confident to administer the morphine when needed. I feel a little hesitant, as I have only given one injection when the nurse was with me. The syringe pump stoped and my husband had no medications for seven hours. We are more aware to check the pump frequently. I have watched the DVD and used the practice kit several times and feel at ease with the project.
I intend to record the use of saline after maxolon to cleanliness of butterfly clip
Having Doctor and nurse support is great but it is good that I can give injections when it is needed to keep [redacted] settled.
I spent a lot of time learning how to open vials and get medications ready. I was disappointed then not to be given the chance to make up medication as my "draw" was that the nurse would prepare all medications. I feel it was a waste of time (for both myself and nurse). It would be better to know "draw" before starting education.
My experience with the education kit, has been a positive one of confidence. The patience of the staff in answering questions about the kit, has resulted in added knowledge of the patient and the care needed to maintain a comfortable existence.
This was a good experience and the face to face session with the demonstration kit made the task much easier. I believe I was better able to take care of mum because of the guidance and education that was received. This gave me a sense of confidence when caring for mum. Excellent idea! Keep up the great work!!
I found the education package to be very helpful, especially the face to face instructions
(Nurse prepared injections; Sorry did not access the DVD) I would not have liked to prepare the injections. Pre-prepared injections by the nurse easy and quick to use. Enough involvement when emotionally distressed without preparing injections or even pre-preparing them.
I found everything is made very easy to follow and understand. Thankyou
Being a first time carer in the home environment I found nursing staff and educational pack a great advantage in the experience of caring for a loved one at home. I feel quite confident in all aspects of care at home.
This experience was very educational, and it really helped with the caring of my mother in law. I also think that more families will care for loved ones using this method, it give you confidence and helps you with understanding the drugs you give to the patient & why they give it.

Questionnaire 1 - Comments
Fridge magnet most useful for other family members; DVD very clear instructions; The combination of practical demonstration & easy to follow written instructions has been very helpful, and the ongoing availability of the service to provide information/reassurance as required is of great benefit. The previous experience of breaking ampoules and drawing up meds for the morphine/saline nebulizer probably made it less daunting. The only concern at first was my accuracy on drawing up 0.25 ml on the 3 ml syringe.
I went through a crash course. I'm [redacted] so I was able to pick it up. But if it was someone who had no nursing experience it would be a mine field for them. But this is my humble opinion I can't speak for other carers. For someone having to use drugs straight away as I did. It would be very daunting and stressful.
Did not get to use the DVD; I wish to record my appreciation to all [redacted] for their constant care and attention. I believe the kit will be very helpful to others who wish to keep family at home.
Extremely good information and service. Could not be happier
A DVD on medication - measuring of doses and filling syringes and labelling them, storing them etc would be helpful- Probably is on the DVD as mine does not play properly - stops part way through
Labels on injections are different to fridge magnet colours marked by nurse very confusing.(Pain white - pain injection is blue)
The only reason some points marked down is because although the training was very helpful only practice will increase the confidence level of administering the injections.
Did not get time to watch DVD
10 Step plan - nothing about labelling doses
Great kit and idea. I thought it would be so easy, but I learnt a few things. The training and training kit is excellent
I have not looked at the DVD that is why I have given it a 4 in the answer above but just having it there to look at if I need it is great. I would give a 7 for liking the fact that it is there if I need it
I found the experience extremely helpful. As yet I have not viewed the DVD. Thank you all for your help and patience.
Did not watch DVD. Education given was sufficient
The contents of the package - especially the guide for caregivers was really useful. The guide for caregivers could also incorporate sticky flags/ stickers to highlight the medications being used. Practical demonstration and demonstrator were extremely helpful / the demonstrator was compassionate and went above and beyond to help. Colours of manual and fridge magnet should match for easy reference. The pen in the kit for the fridge magnet should be permanent.
For me practical is the way. I learn things fast. The [redacted] were very good at running through it. For a better explanation call [redacted]; thank you for your help
After watching DVD and reading booklet, I find it very helpful, although in the orange part of (guide documentation forms pge 48-51, the writing is a bit small not all older people have 20/20 vision, the practical demonstration kit is excellent. Thanks for including us in survey

Questionnaire 1 - Comments
The guide for caregiver is very useful. The registered nurse - demonstrator is very helpful and kind for reduces stress. The colour of the manual and fridge magnet should match. Permanent marker in kit rather than white board marker. Having a visual reference with the DVD is also good.
I've been very grateful for the opportunity as now I'm able to treat my husband as well as care for my husband and now he is able to stay at home where he wishes to pass. Thank you for the opportunity I only hope many other people can follow your guide.
My experience, this kit has been very satisfactory and gave me a great deal of confidence in my role as caregiver for my husband.
This package is a huge support to caregivers who are thrown into areas of care for which they are not equip. The professionals support from the nurses was invaluable and the package a great reference when dealing with this situation. Thank you sincerely for this support.

Questionnaire 2 (Time 2) – Collated summary of lay caregiver's comments

Questionnaire 2 – Comments
Your information came at a time when I was stressed and upset. I should have done all the preparation when I had time to take my time and learn. Learning this when my husband was in pain and going down hill was crazy.
Note that patient passed away shortly after commencement of use of the package therefore was not used longer term (he died later that day)
Since participating in the Caring Safely at Home project my husband, who has [redacted], is at the stage where is requiring regular medication over 24 hours. The course has enabled me to give him his medication. (commented that labels extremely useful rated as an 8)
Knowing how to prepare and administer subcutaneous injections made pain management less stressful for my husband and myself. We knew when the pain hit we were able to do something to try and relieve it immediately without have to sit waiting powerless for someone else to come and do it. I believe it gave me the confidence to keep him at home to the very end.
Returning to you uncompleted as I was not part of the study. The intention was that I would be however when the time came it was not necessary as other family were trained.
I strongly recommend pre prepared measured dosages are the best way to go.
Did not need to administer more than 2 as patient passed away
The assistance given to me was greatly appreciated especially the first couple of weeks of being at home. I would have struggled without this care. To you all, thank you very much for your care and compassion which was greatly appreciated.
By being able to undertake this project I felt that I was able to give my mother the relief from pain and cannot express in words my gratitude for the support and wonderful care given to all the members from the caring safely at home palliative care team "thank you"
The program was excellent and ran smoothly. I was happy to participate in this program. Thanks.
I would just like to add that all the help and care we were given both [redacted] was exceptional, and to be able to assist there people by helping them with your trial was an added bonus and my way of being of help to them. I personally feel, even though I didn't personally use the trial for long, I think it's a great asset and wish you every success with it being successful.
I think the most important aspect for me was that I knew I could give immediate relief to relieve my wife's symptoms, and do it confidently and capably. I found the nurses demonstration the most useful, with the education package as back up reference.
Almost immediately upon being given the "caregiver" role I realised it was going to be too stressful so [redacted] drew up the medication and I was very comfortable with giving the subcutaneous injections. However the training and exposure I'd already received preparing to undertake the role proved invaluable.
I was nervous about giving the injections, but after having the nurse demonstrates to me how, I became quite confident. And I am so pleased now because I was able to keep my daughter at home till the end and that was what she wanted. Thank you

Questionnaire 2 – Comments
I found it very useful to be taught how to preform the injections - even thought I only used it once as mum was taken off the pump after a few weeks.
If ever I had the opportunity again to care for a loved one at home, I would definitely do the same. It was an absolute privilege to be able to care for my darling mother and I can now look back on the 11 weeks that she was under our care with no regrets! (except that I don't still have her) However, I could never have done it without the palliative care team THANK YOU.
I cannot stress enough how helpful it was to go through step by step with someone and have them watch the first injection I gave. However I believe this is because I learn best by 'doing' and we all differently.
Found the nurse showing me was very visual and calming, was comfortable from start and the nursing back up was there if needed. Thank you for the experience was very interesting.
I think it is necessary to have all the bits of the kits even if they aren't all used by all caregivers. We all learn in different ways. Also, it's essential to have all that material to refer to if it is needed (during a crisis for example an or when we say 'oops, what do we do next?) comments from part c As our 'hands on' session was so good, we did not use these (colour coded labels, magnet, booklet) and we had to get straight on with the job of managing my husband's symptoms and giving him comfort.
I have found the project very informative and helpful. I am much more confident (& very scarcely prick myself now) I did not prepare any of the medications given and didn't feel comfortable with the idea of preparing them.
I never had the chance to learn about the administering and preparing of injections because my father passed away. I cannot provide you with any feedback. Thanks.
Didn't have the time (or inclination) to watch a DVD - practical demonstration and supervised first injection best learning method. I would not have liked to draw up injections myself - happier to have [redacted] leave prepared injections.
[redacted] pain and nausea and dizziness were under control with the grasby. The one and only time the injection was given was about 50 minutes before to assist with [redacted] breathing, which it did after about 5 mins he breathing became easier - Since the reason for palliative care is death (for us) we did not understand that the medication we had could help make things easier for [redacted] breathing until we spoke to the on call palliative care nurse. We are satisfied that we did all we could and are happy [redacted] had the needles and it helped him.
I never had a chance to participate in your program because the person we were caring for passed away before we even had a chance to learn. Regards
I did not use the DVD but it made me more relaxed knowing that it was there if I needed it. The first couple of days is the most stressful and if extra help is given at this time (or offered) it makes easing into the process easier. It is the early confidence that needs to be assisted and the kit does that. Knowing you can get a nurse to fill the syringe is also important at the start.
Easy to understand. When time comes education was useful. I'm always ready to learn new things. Confident I will be able to attend to [redacted] Thank you.
[redacted], I was only able to do this for 24 hours before [redacted] needed to be admitted to the [redacted] - where he passed away 5 days later. Thank you for your help.
My husband could not have stayed at home without this aid. It was extremely useful and easy to use. Thank you everybody who was involved.

Questionnaire 2 – Comments
The booklet and DVD should be given to carer at the face to face meeting not locked in the kit - the carer has more time to study before the patient gets to the critical stage. The project made me confident enough to keep my husband at home, the [redacted] were wonderful.
Found it very helpful when it came time to administer drugs to my husband for the help of his pain relief.
I was only able to have patient a home for a week when he was transferred to [redacted]. I did feel in control and confident when he was home giving breakthroughs. The main reason for hospitalisation was the amounts of morphine were greater than we could get from chemist easily and there was little Doctor support at home. The programme is very worthwhile and useful in helping carers. Thank you.
I was instructed by the nurses at the [redacted], and had the support and help at home by the [redacted]. I can not speak highly enough of this service.
I received education then my wife when into hospital, so I never gave an injection
I thank you for my experience as it still gives me the confidence to give [redacted] subcutaneous injections, and also to be able to assist when it is needed not having him in pain for too long, because if I could not help he would have to wait for the nurse to arrive.
I did have some confusion over the amount of morphine in each ampoule. Was not aware that ampoules came in different strengths. I feel it would be beneficial if ALL medication was used in same size syringe that way confusion would not occur.
RN prepared injections due to carer stress
Although I didn't get the chance to administer many injections, I felt confident in doing so and believe it is a very worthwhile project. It could mean the difference between having your loved-one at home with you, rather than in hospital.
As there were two carers - my son in law took the lead. I was rather daunted by the experience but in the future I'm sure I would feel more competent if the need should arise, and am grateful for the experience.
With a [redacted]) it all came back but I was still anxious about over dosing my wife… Just a thought someone who had no background could find it daunting.. I did.. It still haunts me at times if I overdosed her.. But others say NO! my doctor, RN, my boss at work Just a thought.. thank you
Note unable to answer some questions as my mum died within about 15 hours of starting the programme. However [redacted] were very helpful and positive with their instruction. I would like to add that I think it is a brilliant program for anyone wanting to keep loved ones out of the hospital system and the back up support is fantastic Thanks Guys. Please note (demo information) I did not prepare any injections. Had I had longer to become accustomed to the situation, I may have felt competent to draw up the injections. Place in the correct section
The only problem we found has with redrawn medication the plunger stuck. We drew medication back so it would release slowly and not shot out to fast. This information was not given to us and we would have found this useful.
I felt the whole program was extremely good/useful. I was more than impressed with the program and staff could not wish form more 10 times better than in hospital many thanks

Questionnaire 2 – Comments
While I found the experience very useful. Someone with less experience with dealing with medications might find it rather daunting. I worked as a pharmacy technician for many years so, it wasn't daunting for me.
As mentioned, I felt the initial session with the palliative care nurse was too long and would have been better broken down into several sections over a few days. I would have liked help to manage his breathing difficulty during his final day as it seemed a cruel way to spend the last 6-8 hours of his life, needed more preparation about what it could be like as it was not like the booklet.
Thank you for giving me the chance to experience on how to care for my mother-in-law which helped me to cope with her death. The experience gave me more confidence in myself. Even though it was a very short period, I have learnt a lot.
Thank goodness for palliative care as I couldn't have done without them during this time. They have made our lives easier and stress free and I feel so much more confident in administering medications to my husband and understanding pain management for my husband. Thank you so much.
Overall, I found the caring safely at home extremely well prepared and very easy to understand in all aspects of the program. We were able to look after our loved one until the end and felt she was pain free and comfortable. A wonderful program for those competent enough to carry it out.
Did not have time to watch DVD. I found this resource invaluable. I do not have a medical background but it allowed me to have the skills required to respond as required to [redacted] agitation and his pain. It allowed me to get it under control quickly before it escalated out of control. Towards the end a lot more medication was required or less sleep and under high stress. The training and reference itemise allowed me to do this with confidence. It was more than a one person job and we used the diary at all times to check ourselves and each other. I was even able to train [redacted] brother when he arrived. We made a great tag team. Thank you for the resources. We were part of the preloaded syringes which made it much easier. When we had to start loading our own the resources were there in abundance and a bit daunting. The ml to mg could confuse many people especially in a sleep deprived and stressed state. I found myself demonstrating it to Mum with cups of water but to my daughter (16) in a mathematical formula. I feel there could be risks involved doing it this way and the possibility of getting it wrong. The Doctor would have to make sure the pharmacy provided the same strength vials. I cannot thank you enough for all your support.
It was very special to be able to care for my wife in this way. I do think that without the help phone line it would have been to stressful
I found the whole concept of this great, and was made so much easier far. Especially for elderly people, or people with not the best eye sight or confident. I felt very confident on giving my Mum her injections. And this only made it easier. I know this project helped me, and I know it will also help other carers. good luck, and thank you for your support and help.
I was very happy with all the information you gave me it made [redacted] and my life stress free, thank you I no this will help many people God bless -[redacted] only have my mobile if you need to ring me (fridge magnets - very good)
Although the caring period was only a few days, we found that all the information and education sessions were extremely helpful. This made us so much more competent and able to care for my grandmother in her final days. It was very comforting for us all esp. Gran, that she was able to be in her own home.

Appendix 4

Questionnaire 1 – Collated summary of health professional's comments

Questionnaire - comments
Carers should have been allowed to peruse the information kit while they were calm, not stressed with their loved one being in the terminal phase. Labels were far too long - caused frustration. Carers who are already stressed feel overwhelmed with further responsibility if they have to draw up B/T meds, as well as dealing with other cares. The carers felt that the phone calls from 'the research ' team added more stress to them as well as dealing with a service provider already during a 'day'.
I don't feel that I can fill in this questionnaire as accurately as I would like to because of the time gap between participating and receiving this. Would have been better to do when fresh in my mind and looking at the kit. Found I needed to make a few alterations to the laminated prompt sheet to "customise" it for that carer's particular needs / situation. I think with the stickers it would be good to have a printed "sample" as a guide for the carer. Also a little difficult to "line them up" when sticking together on the syringe.
I feel [redacted] already were giving comprehensive education to cares to confidentially and …. Give s/c medications via intima. The project was well organised and the education to carers very helpful. However in the situation it was more time consuming of the nurses.
In an emergency situation I found it all overwhelming for the caregiver. An abundance of information overload for the carer. I believe the project was useful for some and not others. I think we need to be able to adapt our teaching techniques according to how the carer learns. We all absorb information differently. The colour coded stickers were helpful once we could figure out what drug was for what code.
Mostly I think carers felt secure in having the information kits. The education is the same as we routinely do per carers. On the whole I think the project was good we were held back a bit because generally where possible we would teach carers to draw up and give so that was a change to our practice. A lot for cares to take in initially. We tend to stagger our teaching so initially carer wouldn't draw up and then when confident transfer over. Good resources. Labels as you know were a problem due to length, fridge magnet confusing. Thanks
Found the package too in depth and time consuming for staff to explain. Especially if patient deteriorated very quickly o'night. Package was overwhelming to carers. Coloured labels are excellent and diary very good.
The same response has come up over and over again, which was "too much information too soon" "too hard to take everything in". One family stated the [redacted] felt like "being attacked by vultures" as they had not even digested the palliative diagnosis and were overloaded with the project information before even leaving the hospital. Information given of this calibre needs to be delivered in smaller, more appropriate increments.
Require opportunity to teach caregivers using orange needles. All though this is not best practice, many of the carers found this 'easier' than the blunt cannular system and less stressful. Concerns about infection with 'needless' technique, both from carer's and nursing staff.
I felt the package was extremely helpful in providing education to care givers. Two comments: 1. Is worthwhile BUT time consuming compared to not using a standardised package. 2. Carers were far more comfortable with the option of having medication drawn up for them by nurse or pharmacist. The package was extremely helpful and I believe assisted carer's to more ably care for their loved ones at home and also enable the patient to experience a home death comfortably and surrounded by their loved ones.

Questionnaire - comments
Demonstration kit- I always added more equipment. Diary - would simply advise client to record on sheet on fridge or notebook - keep it simple. DVD - only had one client watch it. Seemed to be inconsistency in whether clients were shown to use blunt needles or plastic cannulas. From supporting clients through this project I STRONGLY feel that they should not be expected to draw up the huge amounts of s/c medications that we leave for end of life care. It is useful that we explain to people (should the need arise) but I do not feel it is appropriate / safe. As a trained practitioner it normally takes me at least 1 hour to draw up BT's and we often leave up to 4 different types. (eg Midazolam, Hydromorphone, Maxalon, Haloperidol) - Some of these are also tincy amounts to draw up. I would sincerely question whether any of the carers who are on the "drawing up" arm actually did it. - Often we or the [redacted] nurses actually stepped in. The fact that [redacted] also discards medications within a day also I feel impacted on the project. It both added to the carers stress as they regularly had to draw up medications again. In addition I would question whether adequate amounts were always drawn up as practitioners recognised the huge amounts of daily wastage. Both of these factors I feel impacted on the project in an adverse way.
Needed to plan each visit knowing it was a lengthy process and time consuming. Some carers needed a lot of emotional support around this. Overall, well worth it.
I enjoyed using this package as I felt confident that I had covered all areas that required covering.
DVD no feedback from families
Unfortunately as unable to open information prior to education it meant a lot of time was spent going through the information at time of education. This impacted on time teaching and meant that it took up to 2 hrs out of our day to do the education and if arm 2 - this added again in time to draw up meds for use over next 24 hrs. Otherwise very well planned and easy to use for pt's family. Well done.
Process of education was quite time consuming despite being able to do this in stages (- that was then messy for the carers). Labels fantastic but design could be modified. Would have liked the colour coding in the kit so it was easy to identify. Love the pictorial instruction sheets. Excellent project which will have great benefits for the community in the future.
Demonstration kit needs more ampoules and syringes. Education very time consuming. Fridge magnets not really useful. Overall an excellent package and would love to continue using it.
I found carers were a bit overwhelmed at first with all the information. If there could be another way to provide info without too much too soon.
Carers find any diary writing unless very simplified difficult to do. Excellent programme - but difficult to judge in the community as it is most times a quick process. Labels were to big difficult to manage; diary difficult for some carers to stressful
The program is effective but destined to lose prospective takers when they cannot e assure at the onset that they will only be administering NOT drawing up medications. Carers are often so stressed by their situation that unless they know where they stand when first approached to participate they become overwhelmed with the prospect of taking on what they feel is the nurses role. I would prefer to see a gradual come progressive involvement. eg observe for a period, draw up for a period and finally administer with the RN then independently. (continue with package - the program is great but needs some tweaking. Diary - Some carers sometimes forget entries)
I support this project on an ongoing basis. I do believe that the timing of implementation is critical. Could there be educational information given at OPD appointments? This would save this having to be done when things are at crisis point. The approach to carers needs to be

Questionnaire - comments
managed carefully. Input from the domiciliary staff caring from the client would be helpful.
I never had to assess competence. I did not personally check competence. I think the resource is very useful for training in a standardised manner and to ensure consistency
I have had a few palliative clients in my area of [redacted]. Some clients have declined to go on the programme initially others however have been happy to volunteer and take back some control of there [sic] disease. However I have found that the program only effective with some clients - some clients felt that more education is required and practice with drawing up and administering drugs. More face to face contact. From the providers of the kit!
Client I was involved prepared injections as they were required as they had young children and didn't want to leave prepared medication in the fridge.
Although some caregivers have good intentions to attend medication administration, their anxiety and carer strain impaired ability to absorb learning information from tools quickly. Maybe should be commenced at first visit rather that when client needs s/c breakthrough commenced. Given carer a chance to absorb information prior to 'actual' task. Some carers needed more support therefore more time spent teaching them at times an hour wasn't enough. Most caregivers expressed positive feedback. Need more materials in kit as carer practice once or twice then may not forgetting how to do it 'don't use it you lose it' more water ampoules and sharps containers to dispose? Maybe include journal for carer to write in to reflect or give to them if having issues (a memory pad to ask questions) or white board on the fridge) Pack maybe split in half the theory than practical not all at once might find stressful to seek information.
RN present at time of 'Caring safely at home visit by educator. Family very receptive to education (about for share carers) and benefited from educator, (who had excellent communication skills) input. Palliative care using above project was beneficial for client and carers. Excellent home palliative care given as per clients wishes.
Found resources excellent for carers to refer to and also continuous education. Carer gained confidence in knowledge that additional support available if required. Would definitely like to use resource pack post clinical trial if available.
DVD not seen.
I found the material provided by this study to be of a very high standard and was of a lot of assistance for client's families. Definitely filling a big void in the community for families caring for their relatives.
This was a very beneficial tool for both staff and carers. I hope it continues to be used.
Did not supply enough paperwork to record breakthrough medications. Family / carers were confused about what roles the palliative care teams played in delivering care eg [redacted] care and [redacted]

Appendix 5

Flow of participants through the RCT

