Macmillan Pharmacist Facilitator Project

Six Month Baseline Report – 2010

WE ARE MACMILLAN.
CANCER SUPPORT
Macmillan Pharmacist Facilitator Project

Six Month Baseline Report - 2010

This work was undertaken by the
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Executive Summary

Introduction
In 2009 Macmillan Cancer Support agreed to fund a 3 year project (Jan 2010 – Dec 2012) which would pilot the establishment of 4 Macmillan Pharmacist Facilitators, to be located in 4 CH(C)Ps [South West Glasgow CHCP; West Glasgow CHCP; West Dunbartonshire CHCP; Inverclyde CHP ] in NHS Greater Glasgow and Clyde, and test the ability of these posts to:

- Develop Community Pharmacy capacity to effectively, efficiently and safely support the growing needs of those in local communities with cancer and palliative care needs
- Improve service provision/co-ordination through the enhanced support of Community Pharmacy Networks, ensuring opportunities are developed for training and peer support and providing quality information to support practice.

This report forms the first output from the evaluation and focuses on the initial six month investigation to characterise the current Community Pharmacy service in the study CH(C)Ps and identify service gaps and key issues to inform a quality improvement program.

Method
The study comprised two approaches:

Part 1 – Qualitative study: Group interviews and face-to-face interviews were conducted by members of the university team to elicit the views of Health Care Professionals, Professional Carers and Patients/Family Carers on current pharmacy service provision and areas for improvement. Brief interview schedules were developed based on the study objectives. All interviews were tape-recorded, transcribed verbatim and analysed using the recognised Framework Approach.

Part 2 – Quantitative study: Questionnaires completed by Community Pharmacies and General Practices in the study CH(C)Ps were used to collect exploratory baseline data on: knowledge of the Community Pharmacy Palliative Care Network (CPPCN); palliative care services; sources of Information on palliative care, and;
pharmacy staff training and development. The appointed Macmillan Pharmacist Facilitators co-ordinated questionnaire distribution, completion, tabulation of data and key findings for each CH(C)P. Data were independently reviewed by a member of the university team to identify common themes.

Key Findings

All data collection was undertaken between January and July 2010 in the four CH(C)Ps.

Part 1 – Qualitative study: Participants comprised: 51 health care professionals (35 Palliative Care Network Pharmacists, 14 District Nurses, 2 General Practitioners); 5 Professional Carers, and 16 Patients/Family Carers.

Table 1 presents the key themes identified for each group with some illustrative quotes to reflect both strengths and potential issues/gaps with the current palliative care service.

Part 2 – Quantitative study: Questionnaires were completed by: 85% (n=23) of Network Pharmacies; 93% (n=80) of the Non-Network Pharmacies; 51% (n=55) Practice Managers, and 23% (n=91) of General Practitioners. A standard profile was prepared for each CH(C)P and comprised: population and service overview; CHCP practitioner feedback on palliative care services. In addition two of the CH(C)Ps sought views from district nurses and these findings are available in the individual CH(C)P profiles.

Table 2 presents the range of agreement with a number of parameters across the four CH(C)Ps.
Table 1 – Summary of key themes on current provision of palliative care services.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Theme identified</th>
<th>Strengths of current service provision</th>
<th>Issues &amp; gaps of current service provision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients and Family Carers</td>
<td>Pharmacy Services</td>
<td>“they’re very, very helpful; he has these patches for pain and it was the chemist that recommended them...And she said, we can but try them, [to see] if it helps the pain.”</td>
<td>“I had to go back the same day to the chemists, I’d to get a bus away back to the chemists, a bus to the health centre, and a bus back to the chemists”</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
<td>“..that was another thing, I liked all the liaison...you can see the communication [between members of the healthcare team]– I did think that’s a very important thing.”</td>
<td>“You’d think they would post it [discharge letter to the GP], but they don’t, they give it to you....so we’ve to take it down to the surgery.....we’re two buses or a taxi, because we don’t drive.”</td>
</tr>
<tr>
<td></td>
<td>Other issues</td>
<td>“I generally just phone the District Nurses, I’ve the District Nurses’ number and I phone them ...They’re very good at organising someone to come in, they’ve never let me down yet.”</td>
<td>[NHS24 is] “a frustrating system to use. By the time you get them, for a start… then you answer all their questions, there’s quite a lot.... and you get put onto someone else who asks you the exact same set of questions! And all you’re wanting is assistance”</td>
</tr>
<tr>
<td>Palliative Care Network</td>
<td>The Community Pharmacy Palliative Care Network</td>
<td>“I think the best thing about the network is having the list of drugs, that narrows down what you need to stock and also gives everyone a clear idea of the kind of things that are going to be prescribed…”</td>
<td>“You pick up patients in the final stages of their life who haven’t been your regular patients, they just suddenly appear and you don’t actually know anything about them….”</td>
</tr>
<tr>
<td>Pharmacists</td>
<td>The Dispensing of Palliative Care Medicines</td>
<td>“If it’s urgent then you’ve got to weigh up the benefits, this patient is either going to be in pain to wait to get something on prescription, or you just give them it if you’ve got clarification over the phone.”</td>
<td>“I think that the biggest issue out of hours is the prescriber’s intention. That is the biggest problem we have and if we could have a way to access that information easily and quickly it would save everybody a lot of heartache...”</td>
</tr>
<tr>
<td></td>
<td>Sources of Information</td>
<td>“It’s ... the Palliative Care Formulary. It’s just basically ... goes through each of the drugs that they use and why they use them and it’s kind of a side to the BNF but goes into a bit more explanation.”</td>
<td>“The paper on the shelf is accessible - the computer’s in use, someone’s printing, you want to get on the internet or whatever - it can be time-consuming, it can be restrictive...”</td>
</tr>
</tbody>
</table>
"Most of my counter staff are able to recognise unusual stuff... they are able to recognise most controlled drugs now..."

"...somebody prescribed Hyoscine the other week, a 600 microgram ampoule whereas we always keep 400mcg, that's what's on the list, so you then have to go back and phone and that kind of trying to chase up doctors is, it's a bit of a nightmare."

"I have people come in saying 'I've been out of hospital for a week and I need medicine for tomorrow and all my medications have changed' and I have got no discharge letter and no idea what the medication is that's changed."

"...you're hopefully familiar with your patients who are coming to the stage of a syringe driver - to anticipate the need for this so that you have the prescriptions and medications in the house."

"...we've got a good relationship with the pharmacists."

"...you can't always get through to a doctor, but you can speak to the pharmacist."

"...if the patient is hopefully stable or just has an overriding want to go home... often it seems to happen without very much warning and communication is poor."

"...we've got a good relationship with the District Nurses, General Practitioners, Professional Carers..."
### Table 2: Positive responses to questionnaires distributed within the four study CH(C)Ps

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Network Pharmacists (n=23) (min/max %)</th>
<th>Non Network Pharmacists (n=80) (min/max %)</th>
<th>General Practitioners (n=91) (min/max %)</th>
<th>Practice Managers (n=55) (min/max %)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness of the Community Pharmacy Palliative Care Network?</td>
<td>88 / 100</td>
<td>67 / 87</td>
<td>16 / 74</td>
<td>25 / 100</td>
</tr>
<tr>
<td>Awareness of Nearest Network Pharmacy?</td>
<td>60 / 100</td>
<td>48 / 73</td>
<td>8 / 56</td>
<td>8 / 35</td>
</tr>
<tr>
<td>Approved Palliative Care Medicine List stocked by Network Pharmacy?</td>
<td>83 / 100</td>
<td>47 / 80</td>
<td>13 / 48</td>
<td>0 / 19</td>
</tr>
<tr>
<td>Are contact details of specialist palliative care pharmacists available</td>
<td>67 / 100</td>
<td>19 / 73</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Undertaken palliative care training in the last 3 years?</td>
<td>63 / 100</td>
<td>7 / 27</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Does surgery participate in the Gold Standards Framework?</td>
<td>- *</td>
<td>-</td>
<td>74 / 90</td>
<td>73 / 100</td>
</tr>
<tr>
<td>Does surgery have an updated palliative care register?</td>
<td>-</td>
<td>-</td>
<td>90 / 100</td>
<td>90 / 100</td>
</tr>
<tr>
<td>Support to share information about patients on the palliative care register with Community Pharmacist if patient consents?</td>
<td>-</td>
<td>-</td>
<td>83 / 100</td>
<td>58 / 71</td>
</tr>
</tbody>
</table>

* question not asked
Conclusion

The Scottish Government national action plan “Living and Dying Well in Scotland”, was published in October 2008. The plan sets out a single, cohesive and nationwide approach to ensure the consistent, appropriate and equitable delivery of high quality and person-centred palliative care (based on neither diagnosis nor prognosis but on patient and carer needs). Within NHS GG&C the key platform for embedding this national plan has been the NHS GG&C Living and Dying Well Action Plan which has been informed by the NHS GG&C Palliative Care Health Needs Assessment, published in 2010 and the earlier NHS GG&C Pharmaceutical Palliative Care Health Needs Assessment from which this Macmillan project was established. The following outlines the existing good practice, current challenges and potential future direction:

Existing Good Practice

- Adoption of the Gold Standards Framework and use of the palliative care register with increasing inclusion of non cancer patients on this register, both viewed as driving improvements, particularly in anticipatory care and equity of care.
- Pharmacists engaged in the Community Pharmacy Palliative Care Network identified clear benefits of being part of the network including: agreement of a core medicines list to facilitate rapid supply; access to training and opportunity to discuss clinical practice; connection to specialist advice and the local multidisciplinary team.
- Good relationships between District Nurses and Community Pharmacies supporting service delivery through better understanding of patient needs and timely medicines supply.
- Professional Carers identified District Nurses and Community Pharmacists as accessible and approachable in their support of patients at home.
- Patients/Family Carers praised the support of their Professional Carers and District Nurses in particular, and the connections they have to other health care professionals.
Challenges

Effective engagement and communication between health care professionals, with patients and across care settings, in particular:

- Transfer between hospital and home remains problematic, particularly in regard to variability of information (including GP notification) and medicines/equipment supplied, especially with a Friday discharge.
- Communication between General Practitioners and Community Pharmacists is variable.
- Local engagement and support between network and non-network pharmacies is variable.
- Lack of information / continuity of information for health care professionals and patients, particularly if changing pharmacy to access palliative care medicines.

Limited prescriber awareness of the medicines list held in Network Pharmacies to support rapid access and evidence of significant issues with controlled drug prescribing meeting legal requirements to enable medicine supply.

Several aspects of the medicines supply process remain challenging within the Community Pharmacy setting. These are:

- Identification of palliative care/urgent prescriptions.
- Incomplete dispensing of prescriptions causing inconvenience to carers.
- Difficulties around collection of prescriptions by carers/health care professionals.
- Continuation of medicines supply, in particular relating to monitored dosage systems in circumstances such as hospitalisation or death.
- Ready access to information sources on medicines, including unlicensed medicines, to support patient care for both patients and health care professionals.

Out of hours/weekend services may be compromised through:

- Lack of continuity of service provision in the Community Pharmacy Palliative Care Network at weekends.
• Limited access to specialist advice.
• Minimal or no clinical information transfer to out of hours/weekend services to support patient care and supply of medicines.

Variability in level of service provision reported by patients/family carers from excellent joined up service to disjointed service with particular reference to:
• Challenges and anxieties for carers, particularly sole carers, when required to leave patients to manage logistics across the Primary Care Team
• Co-ordination of health professional visits within the home setting to avoid patient/carers being inundated
• Difficulties in communicating effectively patients’ prognosis to patients/family carers.

Future Direction
The evaluation provides an evidence base to inform and shape activities within the NHS GG&C Palliative Care Managed Clinical Network. In particular it will support the development of an action plan to enhance the effectiveness of the Community Pharmacy Palliative Care Network (CPPCN) to support all pharmacies to deliver palliative care within and across the study CH(C)Ps and provide a focus for the evolving role of the Macmillan Pharmacist Facilitator. Key areas for consideration are:

Support for practitioners engaged in palliative care including consideration of the following:
• Tools to aid practitioners with selection, and the legal requirements for prescribing and monitoring of medicines in palliative care
• Accessible information for all service providers and patients/carers on how to access medicines 24/7
• Access to information resources about medicines used in palliative care
• Clinical information transfer between care settings and to out-of-hours / weekends service providers to provide relevant and up to date patient care plans. This information could potentially be deployed through the evolving electronic palliative care summary (ePCS)
• Developing skills in preparing for difficult conversations with Patients/Family Carers on prognosis and anticipation of death. This could be implemented as part of the current strategy focused on palliative and end of life care including DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation)

• Introduction of the “Just In Case” box within patients home being rolled out across CH(C)Ps.

Improved communication between General Practitioners, District Nurses and Community Pharmacists to support co-ordination and continuity of care through:

• Improved CPPCN awareness.

• Multidisciplinary training/clinical review sessions to support networking to share good practice.

• Sharing information about palliative care patients on the GP register with the patients’ community pharmacist with patients’ consent. This should be supported through application of the NHS GG&C Information Sharing Strategy to the palliative care setting.

Continued integration of the CPPCN within the broader Community Pharmacy Network including:

• Communication with and training of pharmacist locums / non network pharmacies on key components of the network.

• Training of dispensing/technician staff/counter assistants to support engagement with carers/health care professionals in the Community Pharmacy to improve medicines supply and patient/carer support.
1 Introduction

1.1 Palliative Care

Palliative care is defined by the World Health Organization as 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' [1]. Palliative care focuses on the person, not the disease, and applies a holistic approach to meeting the needs of patients, relatives and carers facing progressive illness and bereavement. The word 'palliative' is derived from Latin and means 'relieving without curing' [2].

Due to the fact that the disease is not responsive to curative treatment in the case of patients receiving palliative care the aim is to provide best possible health care services to the patient which positively influence the natural course of illness and offer a support system to help patients live as actively as possible until death. Palliative care provides relief from pain and other distressing symptoms and integrates the psychological and spiritual aspects of patient care. Palliative care is not just about care in the last months, days and hours of a person’s life, but about ensuring quality of life for both patients and families at every stage of the disease process from diagnosis onwards as they learn to live with their condition.

Palliative care is at present most commonly provided to cancer patients with 90% of specialist palliative care being given to cancer patients in Scotland [3]. However, long term conditions such as heart failure, COPD and dementia account for around 60% of all deaths [4]. Consequently it is now generally accepted that people living with serious chronic illnesses such as heart failure, chronic obstructive respiratory disease (COPD), renal impairment or dementia will require palliative care and thus palliative care should be offered more widely and integrated more broadly across the health care services [5,6].
1.2 Health Policy Context

In August 2008 Audit Scotland published a ‘Review of Palliative Care in Scotland’ stating that there was currently no coordinated national strategy for palliative care [3]. The key messages from this report included:

- Significant variation across Scotland in the availability of specialist palliative care services. People with a range of conditions need specialist palliative care but it remains primarily cancer-focused.
- Generalists need increased skills, confidence and support from specialists to improve the palliative care they give to patients and their families.
- Palliative care needs to be better joined up, particularly at night and weekends.
- Family and friends caring for someone with palliative care needs also need support but this is not widely available.

In October 2008 the Scottish Government published ‘Living and Dying Well in Scotland: A national action plan for palliative and end of life care in Scotland’ [7]. ‘Living and Dying Well’ is the first plan for the development of a single, cohesive and nationwide approach to ensure the consistent, appropriate and equitable delivery of high quality and person centred palliative care based on neither diagnosis nor prognosis but on patient and carer needs. The concepts of assessment and review, planning, coordination and delivery of care, of communication and information sharing and of appropriate education and training are addressed in this Action Plan. The Action Plan states that NHS Boards and Community Health Partnerships (CHPs) should take steps to ensure that patients with palliative care needs are included in a palliative care register and are supported by a multidisciplinary team. The Action Plan also emphasises the importance of proactive care planning and anticipatory prescribing to aid the prevention of unnecessary crises and unscheduled hospital admissions, particularly out of hours. This also includes the planning for stages of illness trajectories that are likely to produce changing patient needs in the future. A number of established good practice frameworks are acknowledged as accepted tools within the Action Plan and include:
Gold Standards Framework (GSF)

The Gold Standards Framework is recommended in various palliative care and end of life care publications [3,7-9]. It is a systematic approach to help primary care teams improve the organisation and quality of care for patients nearing the end of life in the community. This tool ensures that palliative care patients are identified, their needs assessed and a care plan initiated. In the UK the GSF can be used for patients with any life limiting illness living at home, in care homes or in community hospitals. Communication and regular team meetings, co-ordination, control of symptoms including anticipatory prescribing, continued learning, carer support through a link with social services and care in the dying phase are key components of the framework [8,10].

The Gold Standards Framework Scotland (GSFS) was introduced in 2003 and is an adapted version of the GSF for implementation within NHS Scotland. The main differences to the core GSF are: addressing the needs of patients from diagnosis onwards; maintaining a GSF palliative care register and advanced care planning, defined as a process of discussion between an individual and their care providers about individual’s concerns, their preferences for types of care and their understanding of their illness and prognosis [8].

Across Scotland, 75% of GP practices are registered as using the GSFS [3]. As of 2009, 80% of GP practices in NHS Greater Glasgow and Clyde were signed up to the GSFS [11].

The most recent development has been the introduction of the electronic Palliative Care Summary (ePCS) in 2009. The ePCS allows, with patient or carer consent, the access to daily updated summary information from GP records for Out-of-Hours services and NHS 24. This facilitates structured and accurate information to be available at all times to support palliative care patients and their families. The ePCS includes: prescribed medication, medical diagnosis, patients’ and carers’ understanding of prognosis, patient wishes about place of care and resuscitation [8,12].
**Liverpool Care Pathway (LCP)**

The ‘Liverpool Care Pathway for the Dying Patient’ is a multi-professional document developed in 1997 which supports the delivery of high quality care in the last hours or days of life. This evidence-based framework provides guidance on the different aspects of care required, including comfort measures, anticipatory prescribing, discontinuation of inappropriate interventions and bereavement care. It is applicable in hospital, hospice, care home and community setting and takes account of the patients’ needs, wishes and preferences. Care of the dying is urgent care and only as good as the team providing it. Thus, a robust continuous education and training programme must underpin the use of the LCP [13-15]. The UK and 13 other countries are registered with the LCP Continuous Quality Programme [16]. A national rollout of this integrated pathway in the UK is recommended by multiple organisations [3,7-9].

In Scotland the LCP is applied by 12 of the 13 voluntary hospices, but only a quarter of District Nurses reported in 2008 that they were currently using the LCP [3]. In NHS GG&C 37% of the GP practices, 33% of the nursing homes and 47% of the wards in the acute operating division are using or are in the process of implementing the LCP [11].

1.3 Pharmacy Policy Context

Complementary to the broader health policy context for palliative care 'The Right Medicine: A Strategy for Pharmaceutical Care in Scotland' was published in 2002 by the Scottish Government. The policy document proposed a better use of pharmacists’ professional competence in planning and delivering services, especially in priority areas such as cancer, heart disease and mental health [17]. This document placed emphasis on the continued development of Pharmaceutical Care Model Schemes including palliative care, initiated in 1999 in collaboration with the Royal Pharmaceutical Society in Scotland. This work has developed and now all NHS Boards have developed Community Pharmacy Palliative Care Networks (CPPCN). Access to specific palliative care medicines within and out-with working hours via this network is a quality standard in all NHS Board areas [18].
Within the NHS GG&C area 71 of the current 312 pharmacies are involved in the Community Pharmacy Palliative Care Network. This network was established in 2001 and is funded by NHS GG&C [11,19,20]. Additional funding from the Scottish Government in 2009-10 permitted an expansion of the network from 52 to 71 pharmacies [21]. The CPPCN co-operation includes: retaining a stock of more specialised medication which may be required for palliative care; a courier service for transport of urgent prescriptions and medicines and provision of advice and support to other pharmacies, GPs and district nurses.

In 2006, a new Community Pharmacy contract was agreed with the Scottish Government to modernise Community Pharmacy practice and to support the delivery of pharmaceutical care. The contract is based on four core services, namely the acute medication service, the minor ailment service, the public health service and the chronic medication service (CMS) [22].

Following a phased implementation of the four elements, CMS started in 2010 [23]. The CMS aims to further develop the role of Community Pharmacists in the management of individual patients and presents a systematic, three-stage approach to the pharmaceutical care of patients with long term conditions such as chronic pain, COPD and heart failure. This model of practice promotes closer collaborative working and therapeutic partnerships between Community Pharmacists, General Medical Practitioners and Patients who live in their own homes or equivalent. It is underpinned by the new policy framework ‘Establishing Effective Therapeutic Partnerships: A generic framework to underpin the Chronic Medication Service element of the Community Pharmacy contract’, published in December 2009 by the Scottish Government.

1.4 Palliative Care Service Delivery - the evidence base
In the UK, palliative care was first recognised as an important element of health services in the 1960s and has been an acknowledged medical speciality since 1987. The UK is among the countries of the WHO European region with the best ratio of palliative care services to population and with the highest level of development of specialised palliative care teams. Also, it has one of the best ratio of specific palliative care beds to population [2,24]. Despite this, gaps in palliative care service
provision and significant variation in the quality of care across Scotland are still reported [3,25].

Palliative care comprises both generalist and specialist palliative care. Generalist palliative care is delivered at home, in care homes and in hospitals by a wide range of health and social care professionals. In 2008, Shipman et al established that there are difficulties in integrating end of life care within routine practice and among other competing priorities for General Practitioners in the community [26]. Furthermore, some patients have more complex needs especially in relation to symptom control and their palliative care has been shown to be best provided by specialist palliative care teams. These are specially trained multi-professional teams that are likely to include Physicians, Nurses, Chaplains, Social Workers, Physiotherapists and Pharmacists. In Scotland, specialist palliative care is available in various settings such as hospice care, home-care teams and hospital teams and research has shown that it is highly valued by those using them. However, in spite of its success specialist palliative care remains in greater demand than the resources available, particularly in terms of numbers of trained Consultants and Nurses [2,27-29].

Public health studies show that there is evidence of inequitable access to palliative care among members of society. Inequity may be randomly distributed by geographical variations in the provision of palliative care or it may affect groups known to be vulnerable to health care inequities such as the less affluent, certain cultural and ethnic groups, the very elderly (defined as over 75 years) and children. Patients with non-malignant conditions might also not be targeted by current palliative care services [6,30-33]. Equity of access to services is therefore a core concept guiding palliative care policy and service delivery [34]. With the enhancement of living conditions and life expectancy, people in developed countries seem to be losing the familiarity that previous generations had with death and dying. Hence, innovative programmes have a role in increasing awareness and educating the public about end-of-life issues and palliative care, particularly in the context of a health service with a historical and persisting focus on 'curing and preventing' (interventions) rather than holistic 'care' (personal overall needs) [6,25,35]. There continue to be societal taboos around the dying process acting as barriers to
carrying out end-of-life research. Consequently, the associated care progression and service development needed to support the establishment of palliative care as an evidence-based speciality is somewhat limited [36].

**Patients Needs**

The assessment of the defined needs of palliative care patients is an essential step to proposing, developing and planning the right and appropriate services. Due to the inherent complexity of the concept of need, various definitions of need have been proposed indicating that 'it may be an illusion to suppose that there might ever be a consensus about the meaning of need' [37]. A core definition of need used in health service research is that of Bradshaw. The sociologist considered need in the context of who defined it and went on to differentiate between four types of need, those being: the individual's felt (wants, wishes and desires) or expressed (vocalised) needs, the professionals' view on what an individual patient needs, the patient’s need for a particular service compared to people with similar socio-demographic characteristics and in receipt of that service [38-40].

In the UK, the NHS Executive defined need within the scope of healthcare as 'the ability of people to benefit from healthcare provision'. This definition implies that solely cost-effective care is relevant and that a need only exists if there is 'capacity to benefit' from a particular healthcare service. Benefit is not restricted to only clinical improvement, but can also include supportive care, informational advice and relief for carers [39,40].

People living with different chronic diseases often have similar needs and concerns. Anxiety is frequently conveyed about the physical symptoms including pain, the effect the illness has on their everyday life and on their family, the social isolation, the uncertainty of their future, as well as religious and spiritual concerns. Patients’ views can vary from those of their health professionals and of the family members caring for them. There is a high variability in the willingness and ability of people to talk about their illness, its prognosis or their own needs [6,41,42].

In a series of semi-structured interviews, conducted by McIlfatrick, informal caregivers and patients receiving palliative care identified the following main areas of
need: social and psychological support; the need for information and choice; financial concerns. The expressed needs all relate to the everyday social and practical aspects of care and overlap with the perceptions of health care professionals and managerial stakeholders and with the findings of a comprehensive literature review [32,43].

As pain affects more than two-thirds of patients with advanced cancer and, towards the end of life, up to 80% of cancer patients, pain management forms an essential part of palliative care [44]. Relief from pain experienced by people with advanced malignant disease can be achieved in over 90% of cases through palliative care, the compliance with clinical guidelines and the availability of effective drugs, including opioids [6,45]. In 2008, an overall level of adherence to cancer pain guidelines of 75% was determined in seven clinical settings in Scotland. Although a good overall guideline adherence was found, a potential for improvement, particularly in relation to pain assessment was identified [46]. The Scottish Intercollegiate Guidelines Network Guideline 'Control of Pain in Adults with Cancer' also recommends that all healthcare professionals involved in cancer and palliative care should be educated and trained in assessing and controlling pain [47].

Over 50% of patients with advanced illness would prefer to be cared for and to die at home [6,29,48,49]. Despite this preference over 50% of people with chronic illnesses in industrialised countries do actually die in hospitals and only 20% of all deaths take place at home. Due to a more predictable disease trajectory, deaths caused by cancer occur more frequently at home compared with deaths from all other causes such as heart disease, COPD or stroke. [3,50].

Thus, it is ethically important to enable people to become involved in the process of decision-making and to make choices about their care [6]. The majority of palliative care patients spend most of their last year of life at home under the care of family, Community Nurses and family Doctors [26]. Caregivers and family members need support in caring for the ill person and in coping with anxiety, depression and social isolation [6,29,41]. Support for carers, good communication and co-ordination of round the clock care are major factors that make the patients’ desire to stay at home possible [10].
Health Professional Education needs

Health care professionals need to be adequately educated and trained in the areas of evaluating prognosis; in assessing, monitoring and treating pain and distressing symptoms; in communicating with patients; and in dealing with ethical issues and helping patients with difficult decisions. Furthermore, the knowledge and skills need to be sustained and kept up to date [6,51]. It is reported that support and guidance from specialists and access to education and training is limited for generalists but is essential since most end-of-life care occurs in a generalist setting rather than in a specialist palliative care setting [3,26].

Effective communication between health professionals and patients is central to improvements in patients' psychological health and pain control. Inadequate or inaccurate professional communication adds to stress, frustration and uncertainty with clear impacts on pain and the patients' quality of life [6,52]. Some clinicians find it difficult to discuss a poor prognosis with their patients [41]. Therefore highly developed communication skills and adequate time are required [53,54].

1.5 Pharmacy Palliative Care Services – the evidence base

In the UK, the clinical knowledge and abilities of Pharmacists have long been insufficiently used. Needham et al. stated that Community Pharmacists can conduct effective clinical interventions to improve personal pharmaceutical palliative care when they are adequately trained and included as integral members of the multi-professional team. In the UK health care system, Community Pharmacists are unlikely to possess the medical background information necessary to make full use of their expertise and to suggest new therapies or to modulate existing ones. Despite pharmacists being one of the most accessible health care professionals, their lack of access to clinical information about the patients’ medical diagnosis restricts the input they are in the position to give [55].

Medicines are one of the most commonly used health care interventions and play a key role in patient care [56]. Symptom management is a cornerstone of palliative care and most symptoms are controlled wholly or in part by the use of medication [2]. Pain, fatigue, weakness and anorexia are the most prevalent symptoms in patients
with advanced cancer. Walsh et al. in a prospective analysis identified that those patients are polysymptomatic, with a median number of symptoms per patient of 11 [57]. It is reported that the number and severity of symptoms increase in conjunction with the progression of the disease. Frequently, this results in complex medication regimens for patients receiving palliative care. There are many opportunities for pharmacists to contribute to the optimal provision of palliative care within multidisciplinary teams including: the management, documentation and review of patients’ medications; the prevention of prescribing errors; the monitoring and anticipation of side effects and drug interactions; the identification of symptom changes; assistance with compliance; the assurance of 24-hour access to specialist medicines; and the provision of pharmaceutical advice to patients, carers and other healthcare professionals [58].

An Australian team of researchers reported the subjectively perceived knowledge issues of Community Pharmacists concerning palliative cancer care. 'Handling of cancer emergencies', 'Complementary and alternative medicines' and 'Methods of drug administration' were the three topics that Pharmacists considered they had the least knowledge of and should therefore be themes addressed in educational programmes [53]. Another study reported that Pharmacists tend to feel uncomfortable in the management of major pain and are lacking in knowledge on the subject of formal pain assessment [59].

One Irish-based study analysed the process by which palliative care patients access prescribed medications. Medications not being in stock in pharmacies and the inability of patients and carers to courier medicines are among the main identified factors causing delay [60].

1.6 Greater Glasgow & Clyde Palliative Care Health Needs Assessment
NHS GG&C is one of the 14 regional NHS Boards and the largest NHS organisation in Scotland. It has a population of 1,116,040 which is almost a quarter of the population of Scotland, and covers a geographical area from Greenock in the West to Easterhouse in the East of Glasgow, and from the shores of Loch Lomond in the North West to the Renfrewshire/Ayrshire borders in the South (66). To manage a wide range of local health services delivered in homes, health centres and clinics
and to meet the health needs of the community, NHS GG&C has established 10 Community Health Partnerships (CHPs) including seven Community Health and Care Partnerships (CH(C)Ps). CH(C)Ps are also responsible for delivering community based social work services. CHPs are single integrated organisations which bring together NHS and local Council representatives for health care CH(C)Ps focus on the integration of primary care and specialist health care services through clinical networks to improve the health and well-being of the population which they serve [61-63].

A Palliative Care Health Needs Assessment was conducted in the Greater Glasgow and Clyde area and published in 2010 in response to the Living and Dying Well Action Plan. Therein, the annual incidence of deaths and socioeconomic deprivation were detected as the two most important factors that influence the population’s palliative care needs. The Health Needs Assessment recognised community nursing services, general medical practice, specialist palliative medicine and pharmacy services as fields that largely meet the needs of the population within NHS GG&C. However, the Health Needs Assessment identified out-of-hours services, comprehensive access to night nursing services, access to specialist professionals, the disadvantages faced by patients with non-malignant conditions and the integration of social care as areas for improvement. Moreover, patients and carers highlighted in a series of group interviews that information on services, forward planning, access to timely and appropriate support, equipment and respite services as essential factors to enabling patients to stay at home [11].

1.7 Greater Glasgow and Clyde Pharmaceutical Palliative Care Health Needs Assessment

In 2002, the Scottish Executive encouraged Specialists in Pharmaceutical Public Health to develop toolkits for assessing the pharmaceutical needs of local populations [17]. The ‘Toolkit for assessing the pharmaceutical needs of populations: Palliative care pharmaceutical services’ was published in 2004 and aimed to provide practical support for pharmacists specialising in palliative care and healthcare planners to undertake health needs assessments. [64].
The national toolkit was utilised to undertake a pharmaceutical palliative care Health Needs Assessment in the former NHS Argyll and Clyde area from 2005 to 2007 [65]. During this period the Argyll and Clyde Health Board was dissolved and incorporated into NHS Highland and NHS GG&C. This Health Needs Assessment aimed to review the current service provision in NHS Argyll and Clyde and focused on three components of pharmaceutical palliative care:

- Assessment of the availability of palliative care medication including unlicensed medicines during and out-with normal working hours.
- Assessment of the pharmaceutical palliative care interventions undertaken in Community Pharmacies.
- Skills of Community Pharmacists involved in pharmaceutical palliative care delivery.

The Health Needs Assessment identified that the majority of network pharmacies had the agreed stock of palliative care medicines. However, problems in obtaining urgently required palliative care medicines frequently resulted from an earlier failure to anticipate changing needs of patients, such as the inability to take oral medication. Further difficulties existed with the supply of medicines after patients’ discharge from hospital, mainly as a result of poor communication and failure to plan ahead. Despite some improvements, difficulties in accessing controlled drugs and palliative care medicine out of hours still occurred.

The prescription of unlicensed medicines and the off-label use of medicines are common in palliative care. According to an Australian study, 85% of hospitalised cancer patients receive at least one medication that is unlicensed or prescribed off-label [66]. In the UK, up to 25% of all medicines prescribed in palliative care are used for an unlicensed indication or given by an unlicensed route [25]. This Health Needs Assessment report found evidence not only of difficulties in accessing unlicensed medicines but also of uncertainties in correctly prescribing or obtaining these.

In respect of pain control, it is reported that although Pharmacists had identified poor control of pain, an inappropriate breakthrough dose or the omission of a laxative, some of them appeared to lack the confidence or expertise to discuss this with the
GP. Community Pharmacists often do not know of a patient’s inclusion on a palliative care register by GP practices as part of the implementation of the GSF. This limits their ability to intervene appropriately, give advice and optimise pharmaceutical palliative care [34].

The NHS GG&C Health Needs Assessment demonstrated that good practice needs to become more widespread and awareness of the Community Pharmacy Palliative Care Network needs to be increased. Recommendations included: regular training and multi-disciplinary peer review meetings; provision of induction training for new pharmacists joining the network; attendance of Community Pharmacists at practice GSF meetings and the notification of the palliative care status of individual patients should therefore become routine; and the transfer of pharmaceutical care issues between different care sectors should be achieved [20].

Building on this Health Needs Assessment, NHS GG&C progressed to seek funding from Macmillan Cancer Support to address the recommendations of the health Needs Assessment and explore a new service delivery model to support achievement of the objectives of the national action plan 'Living and Dying Well' for the local population. The overarching goal was to increase the effectiveness of the CPPCN, awareness of Community Pharmacists’ role, their capacity to deal with patients requiring palliative care support and to effectively manage anticipatory care needs to minimise out-of-hours issues.

2 Macmillan Cancer Support – Macmillan Pharmacist Facilitator Project

Macmillan Cancer Support was founded in 1911 and is now the largest cancer care and support charity in the UK. The organisation provides information, practical, medical, emotional and financial support and improves therein the lives of people affected by cancer and assists their carers, families and the community. Amongst others, Macmillan Cancer Support funds specialist health and social care professionals [67].
In 2009 Macmillan Cancer Support agreed to fund a 3 year project (January 2010 to December 2012) which would pilot the establishment of 4 (each 0.2wte) Macmillan Pharmacist Facilitators, to be located in 4 CH(C)Ps in NHS GG&C and test the ability of these posts to:

- Develop Community Pharmacy capacity to effectively, efficiently and safely support the growing needs of those in local communities with cancer and palliative care needs.
- Improve service provision/co-ordination through the improved support of Community Pharmacy networks, ensuring opportunities are developed for training and peer support and providing quality information to support practice.

Macmillan Cancer Support agreed to fund an evaluation of this new model of service provision. If evaluated positively the output would be used to share with other cancer and palliative care providers across the UK and be promoted as a model which could be replicated. The evaluation would aim to assess the effectiveness of the Macmillan Pharmacist Facilitator role in further developing and supporting the Community Pharmacy network within participating CH(C)Ps. The evaluation would also aim to assess the subsequent impact on communication and co-ordination issues relating to the provision of palliative pharmaceutical care to patients and carers in their local community.

The University of Strathclyde tendered for and secured the opportunity to run a two year evaluation (January 2010 to December 2011). The University team agreed the following aims and objectives for the evaluation with Macmillan Cancer Support and the NHS GG&C Project Steering Group:

2.1 Evaluation Aim
To inform the development of the Palliative Care Pharmacist Facilitator role in delivering a quality improvement programme of patient care services provided by Community Pharmacists.
2.2 Evaluation Objectives

Characterise gaps in current Community Pharmacy service provision affecting:

- patients' access to medicines and pharmaceutical advice.
- suboptimum medicines use and continuity of care.
- inclusion of Community Pharmacists in the health and social care teams providing palliative care.

Facilitate the generation of models of service provision and inform the development of:

- educational interventions needed to support them.
- practical tools to standardise methods for patient assessment, documentation of care delivery and auditing services.
- comparisons of the costs of establishing and maintaining them.

Report on the changes needed in order to address the:

- identified barriers to the inclusion of Community Pharmacists in the health and social care teams.
- job descriptions of Macmillan Pharmacist Facilitators.
- roles of pharmacy support staff.

This report forms the first output from the evaluation and focuses on the initial six month investigation to characterise the current Community Pharmacy service in the study CH(C)Ps and identify service gaps and key issues to inform a quality improvement program.

3 Study Aim and Objectives

3.1 Study Aim

To characterise the current Community Pharmacy service in the study CH(C)Ps and identify service gaps and key issues to inform a quality improvement program.
3.2 Study Objectives

- To elicit the views of health care professionals on current service provision and areas for improvement.
- To elicit the views of patients/carers involved in the support of patients with palliative care needs.
- To identify level of familiarity with and use of services provided by the Community Pharmacy Palliative Care Network amongst Community Pharmacy network members and non-members.
- To establish an illustrative case series in order to illustrate the range of patient needs and impact of gaps in service provision (to be reported separately)
- To develop an individual CH (C)P profile of current services and initial service provider feedback

4 Study Subjects and Setting

4.1 Setting

This study is based within 4 of the 10 Community Health Partnerships within NHS GG&C [19,20]:

- South West Glasgow CH(C)P
- West Glasgow CH(C)P
- West Dunbartonshire CH(C)P
- Inverclyde CHP.

Figure 1 presents the geography of the CH(C)Ps in the context of NHS GG&C. Tables 1 and 2 provide an overview of the CH(C)Ps population and health service provision information.
Table 1: Population Overview [11,68-71]

<table>
<thead>
<tr>
<th></th>
<th>SW Glasgow</th>
<th>West Glasgow</th>
<th>West Dunbartonshire</th>
<th>Inverclyde</th>
<th>Study total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Population (total number)</td>
<td>116,580</td>
<td>138,856</td>
<td>91,240</td>
<td>81,540</td>
<td>428,216</td>
</tr>
<tr>
<td>Elderly (aged &gt;65) [%]</td>
<td>15.5</td>
<td>13.6</td>
<td>16.0</td>
<td>17.3</td>
<td>n/a</td>
</tr>
<tr>
<td>Minority ethnic groups [%]</td>
<td>4.5</td>
<td>6.1</td>
<td>0.7</td>
<td>0.9</td>
<td>n/a</td>
</tr>
<tr>
<td>Cancer patient registrants (mean annual number)</td>
<td>651</td>
<td>707</td>
<td>500</td>
<td>517</td>
<td>2,375</td>
</tr>
<tr>
<td>Cancer deaths (average annual rate 2003-2007)</td>
<td>413</td>
<td>399</td>
<td>300</td>
<td>271</td>
<td>1,383</td>
</tr>
</tbody>
</table>
### Table 2  Health Service Provision [11,72-76]

<table>
<thead>
<tr>
<th>Service</th>
<th>SW Glasgow</th>
<th>West Glasgow</th>
<th>West Dunbartonshire</th>
<th>Inverclyde</th>
<th>Study total</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP practices</td>
<td>26</td>
<td>45</td>
<td>20</td>
<td>16</td>
<td>107</td>
</tr>
<tr>
<td>General Practitioners</td>
<td>113</td>
<td>134</td>
<td>87</td>
<td>66</td>
<td>400</td>
</tr>
<tr>
<td>Community Pharmacies</td>
<td>31</td>
<td>41</td>
<td>21</td>
<td>19</td>
<td>112</td>
</tr>
<tr>
<td>Independents (n ≤4 sites)</td>
<td>15</td>
<td>12</td>
<td>11</td>
<td>12</td>
<td>50</td>
</tr>
<tr>
<td>Chains (n ≥ 5 sites)</td>
<td>16</td>
<td>29</td>
<td>10</td>
<td>7</td>
<td>62</td>
</tr>
<tr>
<td>Palliative care network</td>
<td>8</td>
<td>9</td>
<td>5</td>
<td>4</td>
<td>26</td>
</tr>
<tr>
<td>Pharmacies</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nurses (District Nurses, Practice Nurses)</td>
<td>190</td>
<td>183</td>
<td>118</td>
<td>125</td>
<td>616</td>
</tr>
</tbody>
</table>

### 4.2 Subjects

The subjects comprised the following populations:

- All Community Pharmacists in each of the identified 4 CH(C)Ps
- All General Practice Staff (General Practitioners, District Nurses, Practice Managers) in each of the identified 4 CH(C)Ps
- Purposive sample of patient/carers from across NHS GG&C
- Purposive sample of Community Pharmacy Palliative Care Network Pharmacists from across NHS GG&C
5 Methods

5.1 Stakeholder Engagement

This study was delivered in collaboration with the NHS GG&C Macmillan Pharmacist Facilitator Project Team which comprised the Project lead (Macmillan Specialist Pharmacists in Palliative Care – Mrs Janet Trundle), Project administrator (Carol Andrews) and the four appointed CH(C)Ps Macmillan Pharmacist Facilitators:

- South West Glasgow CH(C)P - Nadia Afzal
- West Glasgow CH(C)P - Karen Menzies
- West Dunbartonshire CH(C)P - Carolyn Mackay
- Inverclyde CHP - Annamarie McGregor

In addition the project is supported by two key groups:

- **Project Evaluation Group**: comprising NHS service representatives / University and NHS Project Team representatives
- **Project Steering Group**: comprising NHS management and project team representatives, funding body, University representatives

5.2 Literature Review

A literature search was conducted in order to identify relevant previous work and experiences in the field of palliative care and pharmacy services. The findings are presented in the introduction.

For the online literature review the biomedical database MEDLINE was accessed and browsed via PubMed. The search was carried out using both MeSH (Medical Subject Headings) vocabulary and plain search terms, either individually or in different combinations. The inclusion criteria comprised articles published between 2010 and around 2000 and publications in English language.

The following were the main search terms considered:
In addition, the Google web search engine, the Google Scholar database indexing full texts of scientific literature and the search engine Bing from Microsoft were used and the web pages of several journals such as the Pharmaceutical Journal and the British Medical Journal were reviewed applying the same keywords. In addition, the websites of a number of professional organisations such as NHS Scotland and related institutions, the Scottish Government, Community Health and Care Partnerships, Audit Scotland, the Scottish Partnership for Palliative Care and the World Health Organisation were searched for government policy documents relating to palliative care.

5.3 PART 1 - Qualitative Study

Methods

Qualitative research aims to study, understand and represent the experiences and perspectives of individuals. It plays a key role in providing insights, explanations and theories of social behaviour and reaches aspects of sensitive and complex views, beliefs, attitudes and interactions. Thus, qualitative approaches allow access to areas not amenable to quantitative research. The use of qualitative research methods has increased in recent years and they are now valuable tools in the methodological tool box of health services and pharmacy practice research [77-80]. Group interviews and face-to-face interviews were deployed in this study. Group interviews are an important and powerful research tool for collecting qualitative information across many contexts to identify and explore current practices within health care. Group interviews are semi-structured meetings with a small group of individuals that are eminently suited to helping members of specific groups articulate and discuss their opinions, attitudes, values, aspirations, needs and concerns related to a single topic. This methodology aims to identify areas of consensus and controversy. Individual face-to-face interviews have been widely used in health care
research. As already mentioned, the term 'semi-structured interview' implies a loose structured interview with open ended questions based on the objectives of the study. This interview technique allows respondents to raise issues they believe are important to the study area so that true feelings can be determined. The questions should be unbiased, sensitive and clear to the interviewee [80,81].

**Qualitative Study Instruments**

In this study, multiple interviews have been conducted to gain insight into the thoughts, feelings and behaviours of different health care professionals and patient/carers involved in the delivery/receipt of palliative care [Table 3]. Semi-structured face-to-face and group interviews were selected and determined as the most appropriate tools of data collection due to the fact that they enable the participants to describe and talk freely about their experiences while retaining a focus on the subjects of interest. A method that facilitates the expression of criticism and the suggestion of different types of solutions is invaluable when the aim is to improve services [78].

Brief interview schedules were developed based on the objectives of the Macmillan Pharmacist Facilitator study and utilised during each interview setting. The interview topic guide for the group interviews with the pharmacists was modified after the first two interviews into a shorter outline which amplified the individual input of the participants. The interviews lasted between 60 and 90 minutes.
Table 3  Study overview

<table>
<thead>
<tr>
<th>Date</th>
<th>Profession/Carers/Patients (n = total number of interviewees)</th>
<th>Number of interviews</th>
<th>Interviewer</th>
<th>Analyst</th>
</tr>
</thead>
<tbody>
<tr>
<td>13 Jan 2010, 11 Feb 2010</td>
<td>Palliative Care Network Pharmacists (n = 35)</td>
<td>5</td>
<td>MB, GA, SMcK</td>
<td>GA, SMcK, SM</td>
</tr>
<tr>
<td>06 May 2010, 11 May 2010</td>
<td>District nurses (n = 12) DN* oral Histories (n = 2)</td>
<td>2</td>
<td>SMcK</td>
<td>SMcK</td>
</tr>
<tr>
<td>15 Apr 2010, 22 Apr 2010</td>
<td>General practitioners (n = 2)</td>
<td>2</td>
<td>GA, SMcK</td>
<td>SM</td>
</tr>
<tr>
<td>29 Apr 2010</td>
<td>Professional carers (n = 5)</td>
<td>1</td>
<td>GA</td>
<td>GA</td>
</tr>
<tr>
<td>29 Apr 2010, 13 July 2010, 20 July 2010</td>
<td>Patients/Family carers (n = 16)</td>
<td>3</td>
<td>SMcK</td>
<td>SMcK</td>
</tr>
</tbody>
</table>

*DN- District Nurse

**Ethical Approval and participant recruitment**

Advice was sought by the NHS Project Lead from the West of Scotland Research Ethics Service. Ethical review under the terms of the Governance Arrangements for Research Ethics Committees (REC) in the UK, was deemed not to be required, based on the following:

- The project is a service development in the area of pharmaceutical palliative care, which will be evaluated.
- Recruitment is invitational and the transcripts from face-to-face interviews and focus groups will be irreversibly anonymised so that the respondent’s identity is fully protected.
- It is not possible to identify the individual from any direct quotation used in the reporting of the project.

The University of Strathclyde Code of Practice on Investigations Involving Human Beings does not apply to work which is part of routine practices in professional contexts, a service evaluation or an audit of an existing service. Service evaluations are conducted solely to define or assess a particular service provided [82,83].
Consequently, ethical approval was not required for the Macmillan Pharmacist Facilitator Project as it evaluates the current pharmaceutical service provision to palliative care patients and intends to identify key areas for investigation and development. In addition, the participants were recruited by the people who deliver the service, in particular the Macmillan Pharmacist Facilitators and the project leads/administrator. All participants received a full explanation of the study and assurances about confidentiality and anonymity.

The interviews were recorded for ease of data collection. However, following the group interviews the contents of the recording were typed and the audio deleted. Any contributions made by the participants were anonymised so that differentiation between participants in the transcripts is not possible. In addition, personal details such as gender and age were not collected. The study pursues a broad approach where the profession as a group and not the individual is the unit of the analysis. A purposive sampling strategy was employed in this study. The researchers’ goal was to identify, select and recruit a range of participants who share some experiences of relevance to the study and who are able to provide in-depth information about the topic of the study [80,84].

**Palliative Care Network Pharmacists** - Palliative Care Network pharmacists from across NHS GG&C were recruited during two training sessions organised by the Area Specialist Pharmacists in Palliative Care. These sessions were considered as a natural forum from where volunteers for the group interviews could be conveniently identified. The group interviews were incorporated into the daily schedule of the training sessions. With regard to the project, the Area Specialists briefed the pharmacists on the need for volunteers and encouraged their participation.

**District Nurses** - The Macmillan Pharmacist Facilitators were encouraged to make contact with local District Nurses, District Nurse Managers and Practice Managers and discuss with them the need for District Nurse volunteers to participate in group interviews. The actual recruitment of District Nurses was co-ordinated by their managers, the project administrators and the University team. Additionally two
District Nurses agreed to participate in a series of telephone dialogues to capture current clinical care issues arising as part of their daily practice (oral histories).

General Practitioners - the Macmillan Pharmacist Facilitator Project Steering Group were asked to identify through their networks General Practitioners who would take part in a semi-structured face-to-face interview.

Professional Carers - The Macmillan Carers service was established in 2003 and is a joint initiative between the Social Work Department in West Dunbartonshire CH(C)P, the NHS and Macmillan Cancer Support which funds this scheme. The service provides supportive palliative care, social and psychological support to enable people affected by cancer to stay in their own home. Those who are caring for a relative or a friend are also offered assistance and respite by the 12 employed professional carers [11]. The manager of the Macmillan Carers service was contacted, the nature of the project explained and a request made for carers to partake in a group interview.

Patients/ Family Carers - The Macmillan Pharmacist Facilitators and members forming the Project Steering and Evaluation Groups were encouraged to identify, through their networks, patients and family carers to participate in group/one to one interviews. The actual recruitment was co-ordinated by the project administrator.

Data Analysis
A wide range of methods to analyse qualitative data have been described and employed. In the present study the Framework approach was selected as the most eligible one. The Framework approach has been developed in the UK specifically for applied policy research. In applied policy research the objectives of the investigation are typically set in advance and shaped by specific information requirements of the funding body, for example a health authority [82-84].

All focus groups and interviews were audio recorded and transcribed verbatim. Using the Framework approach, the following five stages of deductive data analysis were undertaken [85-87]:
1. The original transcripts were read a number of times in order to become familiar with the raw data, to gain an overview of the richness, depth and diversity of the data and to list key ideas and emergent and recurrent themes.

2. A thematic framework which categorises key issues and groups them under main and sub themes was identified and refined, based on the aims and objectives of the study as well as on topics raised by the participants during the focus groups or face-to-face interviews.

3. The thematic framework was applied to all the data of one series of focus groups and interviews respectively. Indexing references are recorded on the margins of each transcript by a descriptive textual system based directly on the framework headings.

4. The data were rearranged according to the appropriate thematic reference and charts were formed for each key subject area. These charts contain distilled summaries of participants' views and experiences.

5. Within the process of mapping and interpretation, the charts were used to define concepts, to map the range and nature of phenomena, to develop strategies and to find associations between themes with a view to providing explanations for the findings.

The transcripts of the five group interviews with the Palliative Care Network pharmacists and the two face-to-face interviews with the General Practitioners were analysed by three members of the University Team. In several team meetings emerging topics were discussed, major themes agreed and coding strategies decided. Remaining discrepancies concerning the framework of themes and the coding categories were resolved by discussion. The subsequent analysis and write-up of each theme was distributed between the researchers. The combination of investigators strengthened and developed the analyses and improved the validity and reliability of the study. Furthermore, exemplary and representative quotations, provided in the report of the results, illustrate the content of the transcripts and demonstrate that the researchers’ interpretations are based on original evidence. Particular attention was devoted to obviating the risk of quotes being taken out of context or becoming distorted [79,88].
5.4 PART 2 – Quantitative Study

To complement the qualitative study it was decided to collect some exploratory baseline data from all Community Pharmacies and General Practices within the study CH(C)Ps.

Questionnaires were designed and piloted for Community Pharmacies and General Practices. The key areas to be explored were identified through discussion between the University and NHS Project Teams and based on local intelligence and review of the NHS Greater Glasgow & Clyde published needs assessments.

The key areas agreed for investigation and the methods of data collection were:

**Community Pharmacy data collection**
- Community Pharmacy Palliative Care Network knowledge
- Sources of Information on palliative care
- Training and development

For Community Pharmacies the appointed Macmillan Pharmacist Facilitator approached all Community Pharmacies within their CH(C)P to administer the questionnaire. Detailed methods are provided in the key findings section for each CH(C)P profile.

**General Practice data collection**
- Pharmacy Palliative Care Network knowledge
- Palliative care services

For General Practices the questionnaires were distributed to all General Practices through local established communication channels identified by the Macmillan Pharmacist Facilitator. The questionnaire was accompanied by an introduction letter and directions for completion by key personnel and mechanism for return of completed questionnaires. Detailed methods are provided in the key findings section for each CH(C)P profile.
Data Analysis
The questionnaires were analysed by the appointed CH(C)P Macmillan Pharmacist Facilitator. Tabulated data were generated for both Community Pharmacy and General Practice settings and key findings summarised for each CH(C)P. These data were then reviewed independently by a member of the University Team to identify common findings and themes which were validated by the four Macmillan Pharmacist Facilitators.

6 Key Findings - PART 1 - Qualitative Study
Analyses of the interviews conducted provide insights into the gaps in current Community Pharmacy service provision and into the role and inclusion of Pharmacists in the multidisciplinary team providing palliative care.

Emergent themes from Community Pharmacy Palliative Care Network Pharmacists:
The Community Pharmacy Palliative Care Network
The Dispensing of Palliative Care Medicines
Sources of Information
Training and Education
Communication
The Role of the Macmillan Pharmacist Facilitator

Emergent themes from District Nurses, Professional Carers and General Practitioners:
Palliative Care Services in General
Pharmacy Services
Communication
Out-of-Hours Issues

Emergent themes from Patients and Family Carers:
Pharmacy Services
Communication
Other issues
6.1 Analysis of the group interviews with Palliative Care Network Pharmacists

The Community Pharmacy Palliative Care Network

When talking about the advantages of being part of the CPPCN many participants mentioned the existence of a specific list of drugs which should be in stock. Furthermore, they said that the availability of a standard set of drugs enables the pharmacies to fulfil the basic medicinal needs of patients and improves access to medicines for the patients.

“I think the best thing about the network is having the list of drugs, that narrows down what you need to stock and also gives everyone a clear idea of the kind of things that are going to be prescribed … that made a huge difference to the way we manage patients.”

On the other hand, some participants stated that the storage of an additional amount of drugs exceeds their physical capacity (storage space).

“I have an issue with storage … the CD cupboard just doesn’t cope with the amount of drugs I have, plus just regular controlled drugs which are subject to safe custody regulations so I’m going to have to invest in a new CD cupboard.”

Many participants appreciated having the ability to phone and make contact with the other network pharmacies, for example to refer patients and to support each other.

“The reassurance that there is support out there, if there is something a bit more unusual comes up, then … you do know where to go; you’re not on your own.”

Several participants acknowledged the opportunity for personal development as another advantage of being a member of the network. They appreciated that an
increase in confidence and knowledge may not only be achieved in day to day practice but also in attending ongoing information courses and updates. Training days are organised by the Specialist Palliative Care pharmacists for the network and provide a chance to meet other members and share experiences.

“The longer you’re doing it, you become more the port of call for either information or whatever and you get more experienced at handling it and you are a source of information yourself.”

“The extra training and the information you are given on the palliative care drugs, you knew a bit more about it than you would if you weren’t part of the network.”

Various participants considered the Pharmacy Taxi Protocol for Palliative Care Medicines to be helpful as a backup in urgent situations, but most of them have never used it. Some participants argue that the taxi protocol is a cumbersome procedure as it involves several steps: engaging a specific taxi company to collect the patient’s prescription and to deliver the medicines, asking the patient to phone the pharmacy to confirm the delivery and obtaining a receipt for taxi fare reimbursement. Therefore, most of the time the pharmacist or members of staff deliver the medicines themselves and at times they use this opportunity to offer support and talk to the patient. Furthermore, several participants expressed reservations about handing medicines, especially controlled drugs, to a non-professional, unauthorised person.

“Kind of personally I just feel safer with one of my members of staff or I doing it than just handing it over to a taxi driver. Even although there is a protocol set up for it, I just don’t feel comfortable with that, especially if it is a controlled drug.”

It was suggested that a potential disadvantage of being a CPPCN Pharmacy is the fact that Pharmacists sometimes have to dispense for patients who have never used that pharmacy before and whom they have never met, which makes it difficult for the pharmacist to check the prescription.

“You pick up patients in the final stages of their life who haven’t been your regular patients, they just suddenly appear and you don’t actually know anything about
them. You’ve got no Patient Medication Record what to check and sort of see what doses they have been on up till then, so it really is a prescription out of the blue ... you’ve got no kind of back up to know that you are dispensing the right thing.”

The dispensing process of palliative care prescriptions

Palliative care medicine list and unfamiliar medicines

Group interview participants discussed the problems that can sometimes affect dispensing if the medicine prescribed is not on the network pharmacies list of drugs or is prescribed in a different strength from that on the list. This can occur because the prescriber has not referred to the list, or perhaps chooses to prescribe a different drug. It often means that the pharmacist has to make phone calls to obtain clarification or to find a supply of the drug concerned.

“They always prescribe a different-sized ampoule or strength of ampoule and you’re always left to phone around to try and get it sorted out, whereas if the prescribers stuck to the list as much as possible that would probably help everything a wee bit.”

“... somebody prescribed hyoscine the other week there, it was a 600 mcg ampoule whereas we always keep 400 mcg, that’s what’s on the list, so you then have to go back and phone and … trying to chase up doctors is a bit of a nightmare.”

“It all depends, of course, if the prescriber is prescribing from our formulary; if they have something that’s not there, if they’ve just decided that they’re having something that’s not on our list, then we’re actually left looking like … you are the palliative care pharmacy for that area, why do you not have it?”

Insufficient supply

Participating network Pharmacists were asked what would happen if they had insufficient stock of a medicine to dispense a prescription in full. Mainly the Pharmacists responded that they would dispense the amount available and then try to obtain a further supply. This could be from another network pharmacy or perhaps from the wholesaler and often the pharmacy might deliver the medicine to the patient’s house when it becomes available.
“If it was required urgently you would source it from a nearby pharmacy, if it’s not urgent you would order it for your next delivery …”

“Dispense the initial quantity and order the rest, and usually you would end up delivering it once it came in.”

“I think the easiest thing to do in that situation would be to phone about network pharmacies and find out someone who could dispense it all.”

**Dispensing out-of-hours**

Network Pharmacists reported that any problems that can occur in the dispensing process would be even greater out of hours. Where the medicine required is not in stock, then the wholesaler, the hospital or the out of hours service are approached for help. However, where the prescription contains an unfamiliar medicine or an unusual dose, this is a harder problem to deal with as it may well be impossible to contact the prescriber or to find suitable sources of information.

“I think that the biggest issue out of hours is the prescriber’s intention. That is the biggest problem we have and if we could have a way to access that information easily and quickly it would save everybody a lot of heartache.”

“... if there’s a strange dose, a palliative care dose that you haven’t seen, there’s no one to check with if it’s out of hours.”

Another issue mentioned by group interview participants was that pharmacy staff, both Pharmacists and support staff, is often different at weekends, which means that they may have less familiarity with palliative care drugs and procedures.

“... I think that is where it falls down at the weekend, because … it’s our pharmacies that are part of the scheme but we are probably not there as palliative pharmacists in the scheme when we are needed most, which is at the weekend and out of hours.”

“... a lot of the time your weekend staff tends to be less experienced and they’re less likely to recognise a prescription that should be brought to your attention right away.”
The recognition of urgent prescriptions

There was some discussion among the participating Pharmacists about how a prescription for palliative care medicine is recognised and how these are dealt with. Many prescriptions are brought in by District Nurses or the GP surgery phones in advance to advise that the prescription is on its way. If this is not the case, the consensus appeared to be that the pharmacist often makes an 'educated guess' based on what drugs are prescribed.

“It’s probably a cocktail of drugs, not just one - there’s injections, there’s tablets, there’s all manner of things - so it’s fairly easy to work that this is what it’s for.”

“You get an idea if it is for syringe driver drugs for example, but then that doesn’t always indicate palliative care use.”

As for how they would deal with a prescription that appeared to be for palliative care medicine, many of the Network Pharmacists suggested that they would treat these as urgent.

“Simply by default, we’ll treat a controlled drug prescription as urgent.”

“It’s treated with a bit more urgency than your inhalers or other prescriptions. But obviously it depends on the workload - you do it promptly.”

“I think it’s supposed to go to the front of the queue ... you do it as quickly as possible.”

Legal versus ethical decisions

The group discussions about problems when a medicine or strength not on the list inevitably led to a debate about what it means for Pharmacists when prescriptions, and in particular palliative care prescriptions, are not written appropriately. This often involves controlled drugs stating 'use as directed', which does not comply with legal requirements. Participating Network Pharmacists described the 'legal versus ethical' dilemma they can face when they are presented with such a prescription: they are very conscious of their responsibility to the patient, but also well aware of the restrictions placed on them by the law.
“It depends on the circumstances whether we would break the law or not, effectively. Bottom line is we always try and look at worst case scenario and what’s best for the patient ...”

“If it’s urgent then you’ve got to weigh up the benefits, this patient is either going to be in pain to wait to get something on prescription, or you just give them it if you’ve got clarification over the phone. As long as you can stand up and defend yourself.”

“... we did a small kind of audit to have a look at our problems and every single controlled drugs script we had during the month of December had ‘to use as directed’ and that also applied to patches. We would have to check with the prescriber.”

“... this morning I had a prescription for diamorphine came down and it just said ‘to be used as directed’ ... I knew the patient was very, very ill but I was left with a handwritten prescription without the full amount of information on it, so it was a bit of a dilemma about how to proceed ...”

Sources of Information

All participants agreed that the Palliative Care Formulary handbook [89] purchased and supplied to all network pharmacies in 2010 is extremely useful in helping them to deal with the clinical aspects of palliative care, particularly in the identification of unlicensed indications and doses of certain drugs.

“It’s ... the Palliative Care Formulary. It’s just basically ... goes through each of the drugs that they use and why they use them and it’s kind of a side to the BNF but goes into a bit more explanation. The PCF will say why its being used, Cimetidine 800 mg twice a day, you might say that you have never seen that before but if you knew it was a palliative care patient then you can check, it’s excessive sweating or something, isn’t it? Yes, something bizarre.”

Participants were extremely complimentary towards the specialist Pharmacists in palliative care who are seen as an approachable and accessible resource. When asked directly where they would go for advice or information, there was always a unanimous reply of the specialist pharmacists’ names.
“They’re the experts and they’ve always responded very promptly, so we’d have no hesitation in contacting any of them.”

It appears that they are often consulted in preference to other, more established resources such as local medicines information centres and several participants recognised that there is perhaps too much reliance on them.

“It appears that they are often consulted in preference to other, more established resources such as local medicines information centres and several participants recognised that there is perhaps too much reliance on them.”

“Put it this way, we wouldn’t phone drug info because it would take 5 years to get the information back.”

During out of hours, most participants mentioned local hospices, specialist pharmacists at local hospitals and the NHS 24 'professional to professional' contact service as their main sources of information.

“If you phone the palliative care pharmacists at the xxx hospital, you can get information from the palliative care specialist doctors as well.”

“I had a script where a patient was changed from buprenorphine to another fentanyl patch and it didn’t seem right, and that was like at 5 o’clock on a Friday, and nobody knew anything. Fortunately one of the consultants was still on at the hospice, and it was one of his patients, so he said no, start him off on a lower strength of fentanyl patch than was originally prescribed by the GP.”

“There is professional to professional lines where you are not just going through the normal out of hours or NHS 24 phone lines, you are actually phoning professionals that only pharmacies have access to ...”

Other reference books such as the British National Formulary were mentioned but their limitations regarding the provision of specific information about palliative care were recognised. The internet was mentioned as a source of information but the practicalities of accessing and being able to browse web pages of interest whilst also being fully engaged in the workings of a busy Community Pharmacy were also highlighted.

“The paper on the shelf is accessible - the computer’s in use, someone’s printing, you want to get on the internet or whatever - it can be time-consuming, it can be
restrictive. Whereas the reference on the shelf, you pick it up, it’s there in black and white - you’re not scrolling up and down the screen. It’s so much better. For me it is, personally.”

Training and education

Participants felt that many of the problems encountered in the delivery of services were actually due to a lack of awareness and training amongst key personnel. All agreed that if pharmacy staff including locums and GPs were better informed then many of the issues routinely encountered would no longer prove to be so problematic.

Pharmacy staff

Pharmacy support staff, with counter assistants in particular and locum Pharmacists were identified as the groups most likely to benefit from further training. Counter assistants are often the first point of contact in the dispensing process and can be instrumental in making sure it runs smoothly. It was recognised that support staff sometimes fail to differentiate palliative care prescriptions or did not appreciate the urgency often associated with them. If they were suitably knowledgeable, then the potential for supply problems would be minimised.

“It’s usually the counter staff who deal with the prescriptions so they’ve got to have some understanding of what’s a palliative care drug and what’s not; so if they know what’s a controlled drug they could ask further questions. Otherwise, it [the prescription] could get lost in the dispensary, you might not see it, but when they recognise the way it’s been written they can ask further questions and distinguish.”

“Most of my counter staff is able to recognise unusual stuff, they are normally quite good at picking out CDs and if it is an injection or even unusual dressings. They’re able to recognise stuff that isn’t run of mill and say ‘do we have this’, and they will show it to you and ask before they put it in the queue.”

The potential for problems is increased out of hours and at weekends. Coincidentally, this is also the period when there may be less experienced or non-routine staff working in the pharmacy. If a locum Pharmacist who is unaware of the
network or its purposes is also in charge, then this could further aggravate an already difficult situation. One participant was particularly vocal about it, saying:

‘you’re a palliative pharmacy, not a palliative pharmacist so the service should be consistent.’

Whilst there was recognition of the difficulty in implementing training for locums, all agreed that systems should be in place to help and guide them, but there was also an expectation that as a pharmacist, they should have sufficient knowledge of certain issues.

“Our locums would normally ask our dispenser and we would usually have ... a senior technician who knew our system and how we manage it and they would guide the locum.”

“... a pack for locums ... just to give them a bit of confidence in what they’re doing if they’re on their own with maybe one junior member of staff. I mean, any pharmacist should be able to deal with any palliative care issue actually.”

**General Practitioners**

General Practitioners were identified as an important group that would benefit from pharmacy focused training. Participants felt that if GPs were more aware of the medicine list and applied it when prescribing, then many of the issues concerned specifically with dispensing would no longer apply.

“Sometimes the prescribers are using drugs that are not on the list. Like midazolam, using a different strength than on the list so the patient comes feeling reassured that you will have all this medication and you actually don’t, so it’s up to you to try and sort that out with the prescriber and inconvenience the patient as little as possible.”

**Communication**

The relative lack of communication and joint working between all health care professionals involved in the care of patients with palliative care needs was seen as a major issue affecting the effective delivery of services. District Nurses, however, were recognised as an important resource and as vital link person that Pharmacists
could consult for information about a patient’s clinical condition or to clarify problems caused by incorrect or incomplete prescriptions.

“... they’re [District Nurses] the ones who’re seeing the patient more regularly than the GPs themselves.”

“If the district nurse is collecting it, they’re quite good because they will say ‘oh right, I will just go back to the surgery and I’ll get it sorted now’ and bring it [the prescription] back round.”

“They can also sort it [the prescription], they can get immediate access to the doctor, and say ‘can you alter that prescription again for me’. And meanwhile you’ve started labelling up the prescription and they bring the new one back rewritten again, and it’s legal.”

Several participants appreciated that District Nurses seem to acknowledge the potential for problems and appear to do their best in trying to minimise these, for example by contacting Pharmacists in advance to pre-empt any supply problems with particular drugs. Furthermore, it was reported that they also use their knowledge of the CPPCN to guide carers as to where to go to get prescriptions dispensed.

“Well obviously district nurses have that list of who is part of the palliative care network and we all have a list of medication that we have to keep in, so it just improves that link. The district nurse can say, go here and get that and they [the carers] are going to come and get it right away rather than having to wait for somebody to order it in and it just kind of improves the service. It means that the patient is getting better care and reducing the kind of distress or anything like that.”

“Prescriptions for palliative care tend to be handed in by nurses. Or they come in and say, we’re going to order this for this patient, when will you have it in, do you have it in? And the family will pick it up this afternoon.”

Another area where communication was particularly lacking was when patients were either admitted to or discharged from hospital or hospice. This often results in the pharmacist being unprepared for actual changes to medication.
“It’s a problem when they’re [the patients] being discharged. I have people come in saying ‘I have been out of hospital for a week and I need medicine for tomorrow and all my medications have changed’ and I have got no discharge letter and no idea what the medication is that’s changed.”

Further problems were associated with the dispensing of weekly compliance boxes. These are blister packs where the medication is organised in compartments by day and time. Considerable time and resource can be spent in the pharmacy in preparing these. Almost all participants had experience of preparing or delivering these to patients that had either been admitted to hospital or had passed away and the pharmacist was not informed.

“It’s not unusual for us to have been delivering dosette boxes to patients week after week and someone phones up and say, my father passed away three weeks ago, can you stop delivering. And we say, we’re very sorry but we didn’t know, no-one’s informed us. I find a lot of times the GPs aren’t told, a lot of my GPs aren’t told at all, it’s the patient that brings in the discharge note.”

The role of the Macmillan pharmacist facilitator

When the participants of the group interviews were asked what kind of support they require from the Macmillan Pharmacist Facilitators in order to provide seamless and effective palliative pharmaceutical care services, they discussed a number of ideas. Suggested tasks included increasing awareness of the network in general, and also establishing a connection with the GP surgeries to ensure that each area of the service is adequately informed about the other.

“Raising profile and awareness of what we are doing but also what everybody else is doing, how we all kind of link into it.”

“... if they can liaise with the surgeries ... sort of make sure that all the surgeries know what’s available in the scheme from our side and also letting us know what the various surgeries are expecting from us.”
Many participants look upon the facilitators as a source of information. To learn from the experiences of other pharmacies through the facilitators was also considered to be important. In addition, some participants recommended the organisation of multidisciplinary courses for them to attend along with District Nurses and GPs, as well as ‘mini training courses’ for the staff within their own pharmacies.

“Keeping us up to date I suppose with any changes. New drugs, new practices. New formulations of existing drugs.”

6.2 Analysis of the group interviews with District Nurses

General comments on the service provided to palliative care patients

Generally speaking, all the District Nurses who took part in the group interviews suggested that the service provided for palliative care patients has improved a great deal over the past few years. An integral part of this improvement is the anticipation of patients’ possible future needs, so that the essential equipment and drugs are either already in place when they become necessary or else can be obtained without delay. This should reduce the need to call out the local out of hours GP services over the weekend.

“I’ve got a patient just now … the palliative care drugs are there, the bolus prescriptions are there and the equipment and the syringe driver are all there should it need to be set up, if someone was called out just to prescribe what to go in it and then the nurses would go and set it up.”

“... you’re hopefully familiar with your patients who are coming to the stage of a syringe driver - to anticipate the need for this so that you have the prescriptions and medications in the house.”

It was noted, however, that there are obvious risks attached to there being a supply of controlled drugs in a patient’s house. The District Nurses explained that patients are given details of how to contact the evening or night nursing service. However, if the patient or family member feels that they want to contact a doctor, they will need to phone NHS 24 who will put them through to the local out of hours GP services.
Several group interview participants mentioned that the adoption of the Liverpool Care Pathway means that care is becoming more standardised and should tend to ensure that nothing is overlooked.

**Pharmacies and the supply of medicines**

The matter of transferring palliative care medicines from the pharmacy to the patient’s house was discussed in the group interviews. The District Nurses confirmed that they are not supposed to carry medicines and that it is normally family members who collect these from the Community Pharmacy. Where no family member is available there is the potential for delay to occur; however, some pharmacies offer a delivery service and the pharmacy taxi service can provide another option. Where there seems to be no other possibility, District Nurses will sometimes collect the drugs from the pharmacy themselves to avoid the patient experiencing any distress.

“I know you aren’t supposed to carry them but I have done it so you can get it set up and you don’t have to pass it to the evening service ...”

“... but we are not covered [by insurance].”

“But you look at the patient and you think, they’ve got pain and they need this and that's what you do.”

The general feeling among the District Nurses was that Community Pharmacists provide a good service and several said that it is helpful to build a good relationship with the pharmacy where they are regular visitors. However, several group interview participants mentioned specific pharmacies where District Nurses waiting to hand in prescriptions are not acknowledged or given any priority and no attempt is made to identify whether the prescription is urgent. It was thought that these pharmacies may have a series of locum pharmacists rather than one or two regular Pharmacists.

“... we've got a good relationship with the pharmacists.”

“It takes time to build it [relationship] up; it's up to the individuals to build it up.”

“I think we have all got our sort of regular pharmacist that you use. The one that's usually closest to you.”
“... the GP had left the prescription so I went down and I was due to finish at 12.30 and I went down there at 12.20 and I was still standing there at 12.55 to get the prescription to take back to the patient.”

“It’s true and the one you’re talking about, they’ll keep you there for ages.”

As far as the supply of drugs is concerned, the District Nurses mentioned that there can sometimes be delays at weekends in finding a pharmacy with the necessary palliative care drugs in stock. It was suggested that even Palliative Care Network Pharmacies can run out of some drugs if there has been an unexpected demand.

“... sometimes we are trying to get it set up, you know the drugs are requested, you know the prescription is over at the chemist and you are hoping to get it set up but sometimes that's going to the evening ... the night girls because the drugs ... just aren’t there and you are having to wait for them coming in.”

Another comment made by several nurses was that it would be helpful and would avoid waste if pharmacies were able to hold a wider range of stock to avoid having to dispose of the portion that is not required.

“... with smaller volumes of, like the diamorphine, so that we’re not destroying so much, there’s not so much wastage ...”

Avoidance of waste was also mentioned by a number of participants in connection with repeat prescriptions. It was suggested that in some pharmacies all medicines on the repeat list are dispensed automatically if the patient does not provide information to the contrary, leading to a build-up of unwanted medicines in some patients’ homes.

**Communication**

The issue of communication was discussed in the group interviews and a number of areas were identified where poor communication could be a problem. One of these areas related to patients being discharged from hospital. The District Nurses said that there is considerable variation in the amount and quality of information they
receive when a patient is about to be discharged. Also, when patients are on a syringe driver at the point of discharge the relevant drugs are meant to accompany them, but on occasion the drugs are missing or are the wrong dose. It was suggested that this is more likely to happen when a patient is discharged from a general ward than from, for example, the Beatson Cancer Centre in Glasgow. This is an inconvenience when it happens during normal hours, but can be a real problem when it happens out of hours.

“... there could be a problem if the correct drugs haven’t come from the hospital … you wouldn’t necessarily know that until you arrive to change the syringe driver ...”

“[Do you think you receive enough information?] It’s a real hotchpotch.”

“It depends on what hospital they come from quite often.”

Another area of communication that was mentioned by the District Nurses as having the potential to be a problem concerned the information that is supposed to be passed by GPs to the out of hours service about palliative care patients. It was reported that there have been complaints from out of hours GPs that they do not always receive handover forms for such patients. Group interview participants suggested that it is also useful to inform the out of hours nurses about patients who are on syringe drivers.

“One of our GPs does out of hours and says that it is a problem with communication that often they don’t get that information about these patients ... the palliative handover forms for out of hours ...”

Some of the District Nurses mentioned that it can occasionally be helpful to know when the patient is being visited by other kinds of nurses, for example the Macmillan nurse. Sometimes the District Nurses have called in to see a patient, only to find that another nurse has visited that same day or on the previous day. The District Nurses suggested that if there were some way of communicating with each other about these visits, then they could attempt to time them more appropriately.

“... the patient's sort of inundated, two nurses in two days, whereas if there was communication, if we knew they were going in, we could say, we’ll go in next week.”
Timing of the patients’ discharge from hospital

Friday discharges were mentioned by several District Nurses as being a common cause of various kinds of problem. As well as having to make sure that the relevant drugs have accompanied the patient, this can also mean identifying what facilities are required in the patient’s home and trying to fill any gaps as a matter of urgency.

“They’re very anxious to get patients out of hospital because of the cost of hospital beds, but we don’t necessarily have more staff to deal with all the early discharges.”

“But we really do get landed with a lot on a Friday, and especially on a holiday weekend.”

“I think with palliative care patients as well, it’s on a Friday, if they want home you know, you’ve to get them home and then they come home and it can be a real nightmare.”
Case Vignettes

The oral history sessions with the two district nurses captured six case vignettes illustrating issues arising with supply of medicines for individual patients from Community Pharmacies. Four of these case vignettes are presented in Table 4.

Table 4: Palliative Care Case Vignettes

**Case 1 – breakdown in ordering system**
A female cancer patient, admitted to the hospice on a Friday was by the Monday extremely keen to return home and so was discharged that day, in something of a hurry. The syringe driver was due to be changed at 3.45 p.m. and this was carried out by the hospice staff before discharge. The District Nurses visited the patient on the Tuesday morning and the syringe driver drug was due to be replaced on Tuesday afternoon. The patient’s husband said that the prescription had been handed in to the Community Pharmacy and the drug was expected to be available that morning.

The nurse suggested phoning the pharmacy to check that the drug was there, but when this was done the answer was negative. Apparently the pharmacist who’d received the prescription had been a locum, who hadn’t ordered the drug from the supplier. Once the pharmacy was alerted to the situation the drug was ordered and arrived in time.

*Although the drug was available when required, the patient had been afraid that it might not arrive in time and had experienced some anxiety.*

**Case 2 – lack of medicine availability from manufacturers / prescription for unusual strength**
A prescription of drugs for the syringe driver of a female cancer patient had been ordered for the weekend, and this involved large doses of metoclopramide and diamorphine. When the nurse arrived in the pharmacy to check that the prescription had been collected she was told that because of a manufacturing problem, the large vials that the GP had prescribed were not available. The pharmacist was unwilling to dispense a different size until a new prescription was obtained.

*The result was that the patient’s syringe driver ran out and there was a one-hour gap until the appropriate drugs were available.*
Case 3 – non-identification of urgent prescription in the pharmacy

An elderly man with heart failure was to start on a syringe pump between the Christmas and New Year period. The GP prescribed the diamorphine and the patient’s son-in-law was dispatched to the pharmacy to collect it. The District Nurses gathered up the pump and all the bits and pieces and went to the house where the patient’s daughter explained that her husband had gone to collect the drug. The Nurses laid out the equipment and waited, until eventually the son-in-law came back and said that he’d had to wait for an hour in the pharmacy for the medicine.

Apparently the pharmacy hadn’t noticed that the prescription was urgent and the son-in-law hadn’t realised that he should point this out to the staff. His wife was furious that he had allowed the delay to occur.

Case 4 – difficulty accessing diamorphine out of hours

On a Friday evening at around 9pm, a GP on duty for the out-of-hours service sought to obtain diamorphine 10mg for a patient in a care home to set up a syringe pump. The extended hours pharmacy in the area had just closed.

He contacted the evening district nursing service, thinking they had a stock of diamorphine for syringe pumps but informed they do not hold drugs. The GP then contacted the out-of-hours hub, who attempted to call out a community pharmacist from a voluntary on-call list. The handler was unsuccessful in contacting a pharmacist.

The GP then went to the local hospital and contacted the on-call pharmacist at 10.45pm, and approached the local hospice at 11pm with a request to supply the drug. Both considered supply should be available from community sources.

After 2 hours trying to obtain diamorphine, the GP prescribed tramadol, prochlorperazine and hyoscine to be given by subcutaneous bolus injection, and this was administered via a butterfly cannula by the District Nurses. When they re-visited the patient 4 hours later to give another dose if required, he was very low but settled and died peacefully a short while later.

The incident was fully investigated and resulted in a number of key actions being taken and identification of a series of learning points cascaded for consideration by the multidisciplinary teams.
6.3 Analysis of the face-to-face interviews with General Practitioners

Palliative care issues
When asked about their views on the main issues affecting people with palliative care needs, the key themes appeared to be symptom control, psychological support, communication with the secondary care team and dealing with the whole patient rather than the disease. In addition, one of the interviews raised the complexity of discharge from hospital. It was stated that the GP practice is often not informed about hospital discharges, particularly when unplanned discharges occur and this lack of communication can result in emergency situations, for example an urgent need of a syringe driver for pain control.

“… if the patient is hopefully stable or just has an overriding want to go home, the patient is discharged home … often it seems to happen without very much warning and communication is poor.”

The communication of a patient’s prognosis and the anticipation of death is a sensitive and demanding topic which is inadequately addressed by health care professionals. This is partly because GPs are concerned about losing the relatives’ confidence and their professional credibility by estimating the patient’s prognosis incorrectly. As a result, carers and family members are not appropriately prepared for the patient’s death.

“It is a very difficult conversation to have with a patient and a patient’s loved one. You know in the abstract it is the right thing to do but it is not an easy thing to say”

Out-of-hours issues
The provision of palliative care services out of hours was extensively discussed in both interviews. One GP mentioned the importance and difficulty of anticipating patients’ needs to help reduce out of hours emergencies and to prevent situations where it is unknown what course of action those normally coordinating the care would have recommended as being appropriate.
“It’s very easy to say this could be anticipated with the benefit of hindsight … it maybe happens sooner than the clinician co-ordinating the care would have anticipated so the doc in the out of hours period is left to deal with the problem.”

With the introduction of the General Medical Services contract in 2004, GPs gave up the responsibility for 24 hour patient care [90]. Since then, GP practices are responsible for their patients from 8 am until 6 pm on weekdays and NHS 24 provides the out of hours services. Despite public criticism of some aspects of the operational performance in 2004 and 2005, it was now positively noted that systems have been improved.

“My impression is that they’re better organised than we ever were when we were just doing our extended rota.”

One GP highlighted the need for up to date information about the procedures involved in accessing palliative care drugs out of hours. Working out of hours is quite uncommon for GPs, so problems with prescription writing and non-formulary drugs can result from this lack of regular practical experience. As people have different learning styles, the GP advocated a multi-channel approach to provide GPs with relevant information on how to obtain palliative care drugs out of hours. Possible ways to supply this information suggested by the interviewee are the integration of training courses into learning sessions conducted by out of hours services, an explicit flow diagram easily accessible at a central place in the practice and clear written communication. However, due account should be taken of the information overload GPs are often confronted with.

“People need to know what their bit and their responsibility is - where they actually get the syringe driver, the syringe and the tubing and who’s going to set it up and all the rest of it.”

One GP made a comment about carrying controlled drugs in the car out of hours:

“I was told – and this is the first time I’ve been told this – I keep my bag in the car if I’m on house calls and I lock the car – and that’s not good enough any more. My bag has to be locked or I have to have a lockable container.”
During one interview, the GP referred to a local baseline audit of palliative care provided by GP practices. According to this audit, GPs have a broad knowledge base in assessing patients’ clinical condition, but are less aware of the psychological support, spiritual and religious needs of the patients and their families. With regard to bereavement care this lack of appropriate communication skills can also present problems out of hours. The GP identified the need for improving respite and bereavement services in the community. He considered community nurses not doctors as the best people to provide psychological support.

“… doctors out of hours … probably see their role as being pronouncing life extinct and having done that, if they have got another half dozen calls at their back, they will be on to the next one …”

One participant is involved in the implementation of the LCP and so mentioned some ongoing work that aims to improve the out of hours services. This includes the use of standard paperwork that will routinely be placed in the house of the patients and will therewith be accessible by all out of hours practitioners. In addition, the LCP will standardise the anticipation of essential drugs that might be needed for the end of life and which are kept in a Just In Case Box at the patient’s home. Nevertheless the GP commented that she would prefer to prescribe accurate drugs adapted to the individual patient and the circumstances rather than use drugs from a standardised list.

**Pharmacy services**

To improve the quality and correctness of palliative care prescriptions one approach suggested was to promote a list of drugs and strengths that are in accordance with the recommendations of the LCP and that are considered to be routinely in stock in most pharmacies. The GP advised that this list should be made available electronically and as a laminated sheet that can be consulted during the out of hours period. One participant would also appreciate further information on approved indications of drugs and on unlicensed medicines that are used as standard in palliative care.
“… if you want to prescribe morphine, either orally or in vials, you don’t know what the usual strengths are … and it’s certainly not to hand in the relatively pressurised situation where you’ve got somebody who’s clearly in pain, the relatives are in a panic, all that kind of stuff … so I write it out the way I want to write it out and that inevitably means a phone call and a rewritten prescription …”

The access to medication out of hours was also regarded as an area with the potential for improvement.

“… her father was dying and it was Christmas, and she said they had a terrible time getting hold of the drugs. Her brother had to go to Dumbarton [about 30 km from Greenock] because that was the only place they could get whatever it was - this was maybe 4 or 5 years ago. But that sort of thing still happens.”

During the interview one GP mentioned that she is not aware of the existence of the CPPCN. Besides, when talking about the role of the pharmacist facilitators the other GP identified the need to educate the wider primary care team about the role of the pharmacy and to specify areas where a pharmacist could add value. He suggested that pharmacists should take the initiative and link with their local practice teams to present themselves as a resource that could be contacted and involved more fully in the care of palliative care patients. Furthermore, he admitted that it would be important to increase and update the prescribers’ knowledge of new and standard palliative care drugs but he was also conscious of the difficulty in changing ingrained routines of some GPs.

“If you have practices who have a well developed team meeting, training structure then ideal for the pharmacist to try and patch in to something like that because as I said earlier palliative care is very much a team approach.”

“… is going to be almost down to the pharmacist and how he or she can build relationships with various teams and knowing that patients are at that stage in their disease.”

One participant illustrated that although a planned approach like palliative care case conferences with a team of Doctors, Nurses and Pharmacists sounds good in theory it is often difficult to co-ordinate and manage such a venture in reality. Additionally,
quick and unexpected changes in the patient’s condition cannot be planned ahead and require an immediate decision from the GP. It was commented that District Nurses are seen as a helpful resource and as a link between GPs and Pharmacists.

“I would write all that [the medication] out, I would phone the district nurses and I would ask them to get a syringe driver, set up the syringe driver and start the drugs in the syringe driver. There might be family available to go and get the prescription; the nurses sometimes would do that too.”

6.4 Analysis of the group interview with professional carers

The Macmillan Carers reported limited direct contact with pharmacy services. This was mainly because medication issues were usually dealt with by the patient’s family, the District Nurses or the Macmillan nurses. Nevertheless, the carers appreciated the role of medication in their client’s lives and from the group interview two main themes emerged.

Medication and prescription issues

The carers are often present when the patient is due to take their medication and saw their role as one of observation and assistance. This included monitoring the quantity of medication at the patients’ home and assisting them with the re-ordering process. They also witnessed many patients struggling with taking their medication. This included remembering to take particular doses or knowing what some medicines are for, especially 'take as needed' drugs for pain. In these situations the carers were forthcoming in suggesting to patients that they request their medication to be dispensed in dosette boxes, but several carers commented that sometimes not all the medication was put into the dosette box and that this could add to the confusion.

“It would be good if on the dosette, they would put on the side what the tablets were for, you know, rather than just writing, aspirin, it’s just a colour to the client and we don’t know what they are for either.”

“Sometimes, they don’t put all the medication in, like the controlled drugs, so you still have to remember to take that, and then keep an eye on it as well, to make sure
that's not running down. Although their other tablets are getting delivered regularly the morphine sometimes isn't.”

Communication

The carers reinforced the perceived lack of communication that often occurs between primary and secondary care services, particularly when the patient is discharged from hospital. They are often witness to situations resulting from poor feedback of changes to prescriptions and commented on the wastage of medicines that can usually result as a consequence of the delivery of prepared dosette boxes.

“They were changing the patch as well. You would go down to collect it, and it would be the same ones as before, and you’d say 'no he’s not on these ones anymore, he’s been changed to xxx patches’, you know and then you would have to go away and come back, that’s a bit of a problem.”

“When they come home from hospital they’ve got a bag this size (visual representation by extending out arms) with their own (previous) medication, and new hospital medication and it just confuses them, they think, I have to take that and that and sometimes it's the same medication.”

However, the carers recognised their limitations, particularly on medication issues but are happy to act as a link person and contact the different health professionals. They were largely complimentary of pharmacy services, particularly with the speed with which prescriptions are dispensed and delivered, and cited the pharmacist as an approachable health care professional.

“We need to make it clear to a lot of families that we are not nurses, they'll ask, 'what does that tablet do' and I’ll say 'listen, I’m sorry, I am not a district nurse, I can find out for you, I can phone the district nurse or I can phone the pharmacist, I can find out for you, I’ll not leave you in the dark'.”

“You can’t always phone a doctor, you can phone a health centre, you know but you can't always get through to a doctor, but you can speak to the pharmacist.”
6.5 Analysis of the group / face-to-face interviews with Patients and Family Carers

Service provided by Community Pharmacy
Some patients felt that they receive excellent support from their Community Pharmacy and many pharmacies deliver the medicines to the patient’s home. It was reported that one pharmacist had visited the house to explain the different medicines to the patient’s wife.

‘...the pharmacist actually came out to the house and went through everything with me...I can’t fault them, they’re really good’.

The same pharmacist gave the patient some nutritional supplements to try in case they might be helpful, and had suggested analgesic patches:

‘...they’re very very helpful; he has these patches for pain and it was the chemist that recommended them, the pharmacist. And she said, we can but try them, [to see] if it helps the pain.’

However two patients complained that one pharmacy consistently dispensed an incomplete supply of their prescribed drugs, necessitating a return visit by the patient each time. On one occasion one of the patients visited the pharmacy and was asked to go to the health centre because the prescription had been changed:

‘I had to go back the same day to the chemists, I’d to get a bus away back to the chemists, a bus to the health centre, and a bus back to the chemists.’

A family carer explained that as a carer for a terminally ill patient, she found it difficult when an incomplete supply had been dispensed because to return to the pharmacy for the balance of the prescribed drugs involved leaving the patient again, which always caused anxiety. The same carer had experienced delays when visiting the pharmacy to collect medicines following a change of prescription.

‘The chemist I went to had a thing, a stand for the prescriptions that were brought in from the health centre and mine might have been at the bottom of the pile. And if
there was a few people coming in with a prescription in their hand, they would all get taken first……because I’d my mother with me, I never really could go out for too long…and I would allot a certain time to go and collect a prescription’

However this carer felt that she had experienced a range of support from Community Pharmacists, with some offering a much better service than others:

‘..the last one was a very young girl; I don’t know if the training’s changed or what, but she seemed to be more up on it. They didn’t have the drugs at that time but she said I’ll definitely have them for tomorrow and I’ll get them sent to you tomorrow for lunchtime. And she did. So that was really good.’

There was some discussion about whether healthcare professionals know which of their patients are receiving palliative care; it was thought that GP practices record this information on their database but Community Pharmacists do not always demonstrate awareness of the situation, even where controlled drugs are being prescribed for the patient.

When asked whether they ever approached the pharmacist for information about their medicines, several patients felt that there was little opportunity to do this as they tend not to see the pharmacist when collecting their prescription. They believed that the pharmacist might not even be on the premises:

‘..when you come back the wee girl behind the counter calls your name and gives you the bag, you never really get a chance to speak to the pharmacist. They don’t come near the counter……they’ve gone somewhere…..that would be better, if you could get more access to the actual pharmacist.’

Communication

Patients and carers were asked if they were ever aware of problems around communication between healthcare professionals. In general, this was not reported as an issue; however one carer commented that when a patient is discharged from the hospital or hospice, it is the patient’s or carer’s responsibility to deliver the discharge letter to the GP who then passes the information to the pharmacist. The
journey to take the letter to the GP practice is not always easy as many patients and carers rely on public transport:

‘You’d think they would post it, but they don’t, they give it to you….so we’ve to take it down to the surgery…..we’re two buses or a taxi, because we don’t drive.’

Two carers reported that they had experienced very good communication between members of the healthcare team:

‘..that was another thing, I liked all the liaison.. you can see the communication – I did think that’s a very important thing because they would come in and then the District Nurses would know, and the doctor, the Macmillan nurse and everything’.

Other issues

When asked who they would contact during the night if they had concerns, a number of patients suggested that they would telephone NHS24. There were mixed views about the ease of using this service; some were quite happy with it but one patient complained that the length of the procedure had caused him problems because of his breathlessness:

‘I’d to repeat it I think about three times…I was dying to argue with them, but I couldn’t – I didn’t have the breath to argue!’

A carer also expressed dissatisfaction with NHS24:

‘..that’s a frustrating system to use. By the time you get them, for a start… then you answer all their questions, there’s quite a lot…. and you get put onto someone else who asks you the exact same set of questions! And all you’re wanting is assistance.’

Most patients reported that they received visits from District Nurses and several praised this service, some in glowing terms. Carers also mentioned that they relied on the District Nursing service and found it completely dependable.

‘Can I say, the nurses at the X Health Centre, the District Nurses – they’re wonderful. Wonderful.’
'I generally just phone the District Nurses, I’ve the District Nurses number and I phone them…..They’re very good, good at organising someone to come in, they’ve never let me down yet.’

‘Oh no, they don’t.’

There was also praise for the support provided by professional carers, although some family members reported that they experienced a break in continuity when the professional carers are moved, which they find difficult.

‘..the carers keep me up to date with services I could get, extra help that I didn’t know about. They’re good for that.’

‘And they’re also good at informing their bosses of anything that needs to be upped. … they have a good idea, the carers, about a lot of things.’

‘And this has happened a number of times now; my mother’s just getting used to a new carer when she gets shifted.’

One carer felt unhappy that her husband had been admitted to hospital and had then spent a day and a night without any of his prescribed medicines, which included insulin.

‘…when he was admitted I gave [the prescription] to them and they saw everything. And there was nothing done about it. So you’ve got to be very alert.’

7 Key Findings Part 2 – Quantitative Study

For each of the four CH(C)Ps a standardised profile was prepared which comprised the following:

- Population and service overview
- CH(C)P practitioner feedback on palliative care services
  - Community Pharmacies
  - General Practices

Analysis of the four CH(C)Ps profiles provide insights into the current palliative care services and the role and inclusion of Pharmacists in the multidisciplinary team providing palliative care services.
7.1 Community Pharmacies
Data for analysis, across the four CH(C)Ps comprised 23 of the 26 palliative care network pharmacies and 80 of the 86 non network pharmacies.

**Network Pharmacies**
The network pharmacies had a good knowledge of the key components of the pharmacy palliative care service. However there was variability (50-80%) in pharmacies knowledge of the contact details for other members of the local palliative care team, apart from the specialist palliative care pharmacist. There was evidence of participation in palliative care training in the last 3 years in 63-100% of the network pharmacies and substantial support for training of technicians/dispensing staff in all 4 CH(C)Ps.

**Non-network Pharmacies**
Awareness of the local CPPCN varied from 67% to 87% across the 4 CH(C)Ps with only 48-73% of pharmacies aware of their nearest network pharmacy. Knowledge of the list of medicines stocked by network pharmacies ranged from 47-80%. Non network pharmacies had quite limited awareness of how to access both the specialist palliative care pharmacist and also other members of their local multidisciplinary palliative care teams. Non network pharmacies reported little participation in palliative care training over the past three years. Support for training of technician/dispensing staff was variable (35-87%), when asked.

The Macmillan Facilitators on reviewing the data from all 4 CH(C)Ps made the following key observations across the CH(C)Ps:

It was evident that Community Pharmacies that participated in the network had a greater knowledge of the network i.e. what was involved and how it operated. This was reiterated by their knowledge of the medicines list stocked and the transport facility for medicines transfer. The differential between network and non-network pharmacies was less clear in terms of knowledge of where the closest network pharmacy was located to their own pharmacy.
With regard to sources of information for palliative care the network pharmacies were more likely to be aware of the existence of specialist palliative care Pharmacists and a fair proportion had their contact details.

Pharmacists working in pharmacies participating in the network had clearly received more palliative care training in the last 3 years than non-network pharmacies. There was broad support across network pharmacies for training technical / dispensing staff in palliative care but this was more variable for non-network pharmacies.

7.2 General Practices

Data for analysis, across the four CH(C)Ps was provided by 91 of the 400 General Practitioners and 55 Practice Managers from the 107 General Practices. Two CH(C)Ps also actively sought views from District Nurses and these are available in the individual CH(C)P profiles.

Awareness of the pharmacy palliative care network ranged from 16-74% for general practitioners and 25-100% for Practice Managers. Specific knowledge of their nearest pharmacy was poorer at 8-56% for GPs and 8-35% for Practice Managers. General practitioners knowledge of the palliative care medicine stock list ranged from 13-48%.

In contrast, participation in the GSF, maintenance of an updated palliative care register and inclusion of non cancer patients on the register was very high. There was strong support from General Practitioners for the idea of sharing information on palliative care patients on the register with the patient's community pharmacist provided there was patient consent (83-100%).

The Macmillan Facilitators on review of the data from all 4 CH(C)Ps made the following key observations across the CH(C)Ps:

GPs had some awareness of the existence of the network but were less likely to know where the nearest network pharmacy was located. Their knowledge of which drugs were stocked as part of the scheme was of a similar level and they were even less likely to have a copy or access to a copy of the network leaflet. The knowledge
of Practice Managers with regard to all aspects of the Pharmacy Palliative Care Network was variable and fairly limited across all four CH(C)Ps. District Nurse data from two CH(C)Ps indicated a better knowledge of the network pharmacies.

The majority of CH(C)Ps participants knew that their practices participated in the Gold Standards Framework. The Palliative Care Registers were updated and in most cases non-malignant patients were included on the register. A large number of practices reported they had regular multidisciplinary palliative care meetings. There was considerable support amongst GPs for sharing of information with the patient's regular community pharmacist.
7.3 CH(C)P Profile: West Dunbartonshire

Section 1: Population and Service Overview

Demography

<table>
<thead>
<tr>
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<th>West Dunbartonshire</th>
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<tbody>
<tr>
<td>CH(C)P Population (total number)</td>
<td>91,240</td>
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<tr>
<td>Elderly population (aged 65+) [%]</td>
<td>16.0</td>
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<td>Minority ethnic groups [%]</td>
<td>0.7</td>
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<tr>
<td>Cancer patient registrants (mean annual number)</td>
<td>500</td>
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<td>Cancer deaths (average annual rate 2003-2007)</td>
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Health Service Provision

<table>
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<tr>
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<tbody>
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<tr>
<td>Number of GPs</td>
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<tr>
<td>Number of Community Pharmacies</td>
<td>21</td>
</tr>
<tr>
<td>• Independents (n≤4)</td>
<td>11</td>
</tr>
<tr>
<td>• Chains ( n≥5)</td>
<td>10</td>
</tr>
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<tr>
<td>• Chains (n≥5 sites)</td>
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<td>Specialist Palliative Care Services</td>
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<td>CH(C)P Living and Dying Well Action Plan</td>
<td>yes</td>
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<tr>
<td>CH(C)P multidisciplinary team Palliative care network</td>
<td>yes</td>
</tr>
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</table>

* CH(C)P has access to palliative care beds and specialists

Reference materials sourced to complete CH(C)P profile

Demography

A Community Health and Wellbeing Profile of … Glasgow Centre for Population Health. 2008

Health service provision

GP Practices, Community Pharmacies, Palliative Care Network Pharmacies:  
http://www.chps.org.uk/content/ and related websites

GPs 2009:  
http://www.isdscotland.org/isd/5385.html

Palliative care beds: Small Area Population Estimates (SAPE) General Register Office for Scotland (GROS)
Section 2: CH(C)P Practitioner Feedback on Palliative Care Services

CH(C)P Name: West Dunbartonshire

Method
Questionnaires were designed and piloted for Community Pharmacies and General Practices. These questionnaires were then completed for each setting as detailed below, analysed and key findings summarised by the newly appointed CH(C)P Macmillan Pharmacist Facilitator.

Community Pharmacy data collection
The Macmillan Pharmacist Facilitator visited 20 (15 non-network, 5 network) of the 21 Community Pharmacies between 2nd February to 1st April 2010. These visits were pre-arranged and were completed on first visit in all but one pharmacy which was re-scheduled. The time spent in each pharmacy averaged 25-30mins. The 20 Pharmacists comprised either the regular pharmacist or the manager.

General Practice data collection
An introductory letter with the questionnaire was distributed in March 2010 to all 20 General Practices requesting that a nominated GP, Practice Manager (PM) and District Nurse separately complete the questionnaire for each practice. This process was supported by the CH(C)P Prescribing Support Teams who were asked to distribute the questionnaire by hand to each of their practices with returns directed to the Prescribing Team base for collection. From the 12 practices which responded a total of 38 questionnaires were analysed comprising 15 GPs, 12 PM and 11 DN.

Key Findings
Table A and B present the responses to the core questions asked of Community Pharmacies and General Practices in West Dunbartonshire CH(C)P. The key findings identified by the Macmillan Pharmacist Facilitator on analysis of the data are summarised below:
Community Pharmacy

- Community Pharmacists (both network and non-network) were aware of Specialist Palliative Care Pharmacists but network pharmacies were more likely to have their contact details.
- Network pharmacies were more likely to have direct contact details for District Nurses.
- Very few Community Pharmacies had contact details for other members of the local multidisciplinary palliative care team.
- Information resources for palliative care within non-network pharmacies is extremely poor.
- The internet is not a readily accessible method of accessing palliative care information for Community Pharmacists.
- There was substantial support for palliative care training for technical staff within Community Pharmacies.

Table A: West Dunbartonshire Community Pharmacy responses to exploratory questionnaire (n=20)

<table>
<thead>
<tr>
<th>% Network Pharmacists (n = 5)</th>
<th>% Non Network Pharmacists (n = 15)</th>
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<tbody>
<tr>
<td><strong>Network Knowledge</strong></td>
<td></td>
</tr>
<tr>
<td>Pharmacy palliative care network</td>
<td>100  87</td>
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<tr>
<td>Nearest network pharmacy</td>
<td>60  69</td>
</tr>
<tr>
<td>The medicines list stocked by network pharmacy</td>
<td>100  80</td>
</tr>
<tr>
<td>Transport facility/protocol for medicines transfer</td>
<td>100  67</td>
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<tr>
<td>Awareness of CD requisition forms</td>
<td>60  20</td>
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<td><strong>Sources of Information</strong></td>
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<tr>
<td>Specialist palliative care pharmacists</td>
<td>100  60</td>
</tr>
<tr>
<td>Contact details of the above</td>
<td>60  27</td>
</tr>
<tr>
<td>Contact details of other relevant members of multidisciplinary palliative care team (varied for different team members – District Nurses highest)</td>
<td>80  7</td>
</tr>
<tr>
<td><strong>Training</strong></td>
<td></td>
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<tr>
<td>Palliative care training in the last 3 years</td>
<td>80  7</td>
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<tr>
<td>NES Palliative Care training completed</td>
<td>60  27</td>
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<tr>
<td>NES distance learning pack completed</td>
<td>n/a 0</td>
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<td>Support of idea that technician/dispenser receives palliative care training</td>
<td>80  40</td>
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n/a – not asked
**General Practices**

- Knowledge of Palliative Pharmacy network by Practice staff (GP and Practice manager) was much poorer than expected
- District Nursing staff were highly aware of the Palliative Pharmacy network but weren’t so aware of the Pharmacy located nearest to their work base
- Practices demonstrated a high degree of willingness to share patient details for those on the palliative care register but it was less clear whether the practices actually held the details of the patient’s nominated Community Pharmacy
- Need to increase awareness among GP Practice staff of Palliative Care Pharmacy network and access to information via these pharmacies and via Specialist Palliative Care Pharmacists

**Table B: West Dunbartonshire General Practice responses to exploratory questionnaires (n=38 questionnaires)**

<table>
<thead>
<tr>
<th></th>
<th>% General Practitioners (n = 15)</th>
<th>% Practice Managers (n = 12)</th>
<th>% District Nurses (n=11)</th>
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<tbody>
<tr>
<td><strong>Network Knowledge</strong></td>
<td></td>
<td></td>
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<tr>
<td>Community Pharmacy Palliative Care Network</td>
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<td>Nearest network pharmacy</td>
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<td>The medicines list stocked by network pharmacy</td>
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<td>Copy of network leaflet</td>
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<td>7</td>
<td>82</td>
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<td>13</td>
<td>0</td>
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<td><strong>Palliative Care Services</strong></td>
<td></td>
<td></td>
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<tr>
<td>Participation with Gold Standards Framework</td>
<td>75</td>
<td>75</td>
<td>92</td>
</tr>
<tr>
<td>Updated Palliative care register</td>
<td>100</td>
<td>100</td>
<td>92</td>
</tr>
<tr>
<td>Inclusion of non-cancer patients on Palliative care register</td>
<td>92</td>
<td>92</td>
<td>92</td>
</tr>
<tr>
<td>Staff trained to carry out Liverpool Care Pathway</td>
<td>n/a</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Support of idea to share information about these patients with their regular community pharmacist provided there is patient consent</td>
<td>83</td>
<td>58</td>
<td>58</td>
</tr>
<tr>
<td>Regular Palliative Care Multidisciplinary Team meetings</td>
<td>92</td>
<td>100</td>
<td>58</td>
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n/a – not asked
Section 1: Population and Service Overview

Demography

<table>
<thead>
<tr>
<th></th>
<th>West Glasgow</th>
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<tbody>
<tr>
<td>CH(C)P Population (total number)</td>
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<td>Elderly population (aged 65+) [%]</td>
<td>13.6</td>
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<td>Minority ethnic groups [%]</td>
<td>6.1</td>
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<tr>
<td>Cancer patient registrants (mean annual number)</td>
<td>707</td>
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<td>Cancer deaths (average annual rate 2003-2007)</td>
<td>399</td>
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Health Service Provision

<table>
<thead>
<tr>
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</tr>
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<tbody>
<tr>
<td>Number of GP Practices</td>
<td>45</td>
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<tr>
<td>Number of GPs</td>
<td>134</td>
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<tr>
<td>Number of Community Pharmacies</td>
<td>41</td>
</tr>
<tr>
<td>• Independents (n≤4)</td>
<td>12</td>
</tr>
<tr>
<td>• Chains ( n≥5)</td>
<td>29</td>
</tr>
<tr>
<td>Palliative Care Network Pharmacies</td>
<td>9</td>
</tr>
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<td>• Independents (n≤ 4 sites)</td>
<td>3</td>
</tr>
<tr>
<td>• Chains (n≥5 sites)</td>
<td>6</td>
</tr>
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<td>Nurses (DN, Practice Nurses)</td>
<td>183</td>
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<tr>
<td>Specialist Palliative Care Services</td>
<td>*</td>
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<tr>
<td>CH(C)P Living and Dying Well Action Plan</td>
<td>yes</td>
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<tr>
<td>CH(C)P multidisciplinary team Palliative care network</td>
<td>Early stages of set up</td>
</tr>
</tbody>
</table>

* CH(C)P has access to palliative care beds and specialists

Reference materials sourced to complete CH(C)P profile

Demography
A Community Health and Wellbeing Profile of … Glasgow Centre for Population Health. 2008
Health service provision
GP Practices, Community Pharmacies, Palliative Care Network Pharmacies:
http://www.chphs.org.uk/content/ and related websites
GPs 2009:
http://www.isdscotland.org/isd/5385.html
Palliative care beds: Small Area Population Estimates (SAPE) General Register Office for Scotland (GROS)
Section 2: CH(C)P Practitioner Feedback on Palliative Care Services

CH(C)P Name: West Glasgow

Method
Questionnaires were designed and pilot ed for Community Pharmacies and General Practices. These questionnaires were then completed for each setting as detailed below, analysed and key findings summarised by the newly appointed CH(C)P Macmillan Pharmacist Facilitator.

Community Pharmacy data collection
The Macmillan Pharmacist Facilitator visited 33 (27 non-network, 6 network) of the 41 Community Pharmacies between 4th February to 15th March 2010. These visits were a mixture of pre-arranged and unarranged visits following distribution of an introductory letter outlining the project to all CH(C)P Community Pharmacies. The time spent in each pharmacy averaged 20mins (range 15 – 50minutes). The 33 Pharmacists comprised 12 Managers; 9 Pharmacists; 12 locums.

General Practice data collection
An introductory letter with the questionnaire was distributed between beginning of March and end of April 2010 to all 45 General Practices requesting that a nominated GP and Practice Manager separately complete the questionnaire for each practice. This process was supported by the CH(C)P Clinical Prescribing Lead briefing the CH(C)P Prescribing Support Pharmacists (PSPs) at their regular team meeting. The PSPs distributed the questionnaires to their practices with returns either directed to the PSP or posted direct to the Macmillan Pharmacist Facilitator. From the 38 practices which responded a total of 53 questionnaires were analysed comprising 27 GP’s and 26 PM’s.

Key Findings
Table A and B present the responses to the core questions asked of Community Pharmacies and General Practices in West Glasgow CH(C)P. The key findings identified by the Macmillan Pharmacist Facilitator on analysis of the data are summarised below:
Community Pharmacy

- The network leaflet was not widely known about or used; only 7% of non-network pharmacies had a copy.
- None of the non-network pharmacies had contact details of the specialist palliative care Pharmacists and only 50% of network pharmacies had any OOH contact details for hospice or DN's.
- Of the 27 non-network pharmacies visited, 11 were staffed by locums on that day; their knowledge of the network, contact details and information sources was very poor.
- Access to the internet for information resources is restricted in all Boots and Lloyds pharmacies.
- Knowledge of taxi protocol and CD requisition form poor in non-network pharmacies.
- Only 19% of non-network pharmacies have had any palliative care training in last 3 years, but many showed an interest in receiving training.
- Pharmacists feel out of information loop re palliative patients, have to guess if script for palliative patient.
- Not all pharmacies prioritise palliative script as urgent.
- Only 48% of non-network pharmacies knew where their nearest network pharmacy was.
- 74% of non network pharmacies have no palliative care information sources.

Table A: West Glasgow Community Pharmacy responses to exploratory questionnaire (n=33)

<table>
<thead>
<tr>
<th></th>
<th>% Network Pharmacists (n = 6)</th>
<th>% Non Network Pharmacists (n = 27)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Network Knowledge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pharmacy palliative care network</td>
<td>100</td>
<td>78</td>
</tr>
<tr>
<td>Nearest network pharmacy</td>
<td>83</td>
<td>48</td>
</tr>
<tr>
<td>The medicines list stocked by network pharmacy</td>
<td>83</td>
<td>56</td>
</tr>
<tr>
<td>Transport facility/protocol for medicines transfer</td>
<td>83</td>
<td>7</td>
</tr>
<tr>
<td>Awareness of CD requisition forms</td>
<td>67</td>
<td>22</td>
</tr>
<tr>
<td>Sources of Information</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialist palliative care pharmacists</td>
<td>67</td>
<td>19</td>
</tr>
<tr>
<td>Contact details of the above</td>
<td>67</td>
<td>0</td>
</tr>
<tr>
<td>Contact details of other relevant members of multidisciplinary palliative care team (at least one)</td>
<td>50</td>
<td>11</td>
</tr>
<tr>
<td>Training</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative care training in the last 3 years</td>
<td>67</td>
<td>19</td>
</tr>
<tr>
<td>NES Palliative Care training completed</td>
<td>33</td>
<td>11</td>
</tr>
<tr>
<td>NES distance learning pack completed</td>
<td>17</td>
<td>4</td>
</tr>
<tr>
<td><strong>Cannot ascertain whether it is distance learning or palliative care training therefore assuming it is distance learning</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support of idea that technician/dispenser receives palliative care training</td>
<td>100</td>
<td>n/a</td>
</tr>
</tbody>
</table>
**General Practices**

- Majority of GP’s but only 42% of PM’s knew about network
- 56% of GP’s knew nearest network pharmacy but only 35% of PM’s knew.
- Less than 20% had a copy of leaflet or knew how to access it.
- 93% of GP’s were willing to share info with regular CP with patient consent.
- 74% of practices are in GSF and 100% keep an updated palliative care register, 59% say they have been trained in LCP, 85% have regular MD team meetings, 89% include non cancer patients on register.

**Table B: West Glasgow General Practice responses to exploratory questionnaires (n=53 questionnaires)**

<table>
<thead>
<tr>
<th></th>
<th>% General Practitioners (n = 27)</th>
<th>% Practice Managers (n = 26)</th>
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</thead>
<tbody>
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<td><strong>Network Knowledge</strong></td>
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<td></td>
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<tr>
<td>Community Pharmacy palliative care network</td>
<td>74</td>
<td>42</td>
</tr>
<tr>
<td>Nearest network pharmacy</td>
<td>56</td>
<td>35</td>
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<tr>
<td>The medicines list stocked by network pharmacy</td>
<td>48</td>
<td>19</td>
</tr>
<tr>
<td>Copy of network leaflet</td>
<td>19</td>
<td>15</td>
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<tr>
<td>Access to the network leaflet (including on-line)</td>
<td>7</td>
<td>15</td>
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<tr>
<td><strong>Palliative Care Services</strong></td>
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<td></td>
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<tr>
<td>Participation with Gold Standards Framework</td>
<td>74</td>
<td>73</td>
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<tr>
<td>Updated Palliative care register</td>
<td>100</td>
<td>96</td>
</tr>
<tr>
<td>Inclusion of non-cancer patients on Palliative care register</td>
<td>89</td>
<td>85</td>
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<tr>
<td>Staff trained to carry out Liverpool Care Pathway</td>
<td>59</td>
<td>58</td>
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<tr>
<td>Support of idea to share information about these patients with their regular community pharmacist provided there is patient consent</td>
<td>93</td>
<td>65</td>
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<td>Regular Palliative Care Multidisciplinary Team meetings</td>
<td>85</td>
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7.5 CH(C)P Profile: South West Glasgow

Section 1: Population and Service Overview

Demography

<table>
<thead>
<tr>
<th>Metric</th>
<th>South West</th>
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<tbody>
<tr>
<td>CH(C)P Population (total number)</td>
<td>116,580</td>
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<td>Elderly population (aged 65+) [%]</td>
<td>15.5</td>
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<td>Minority ethnic groups [%]</td>
<td>4.5</td>
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<td>Cancer patient registrants (mean annual number)</td>
<td>651</td>
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<td>Cancer deaths (average annual rate 2003-2007)</td>
<td>413</td>
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Health Service Provision

<table>
<thead>
<tr>
<th>Service</th>
<th>South West</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of GP Practices</td>
<td>26</td>
</tr>
<tr>
<td>Number of GPs</td>
<td>113</td>
</tr>
<tr>
<td>Number of Community Pharmacies</td>
<td>31</td>
</tr>
<tr>
<td>Independents (n≤4)</td>
<td>12</td>
</tr>
<tr>
<td>Chains (n≥5)</td>
<td>19</td>
</tr>
<tr>
<td>Palliative Care Network Pharmacies</td>
<td>8</td>
</tr>
<tr>
<td>Independents (n≤4 sites)</td>
<td></td>
</tr>
<tr>
<td>Chains (n≥5 sites)</td>
<td></td>
</tr>
<tr>
<td>Nurses (DN, Practice Nurses)</td>
<td>190</td>
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<td>Specialist Palliative Care Services</td>
<td>*</td>
</tr>
<tr>
<td>CH(C)P Living and Dying Well Action Plan</td>
<td>Yes</td>
</tr>
<tr>
<td>CH(C)P multidisciplinary team Palliative care network</td>
<td>Yes</td>
</tr>
</tbody>
</table>

* CH(C)P has access to palliative care beds and specialists

Reference materials sourced to complete CH(C)P profile Demography

A Community Health and Wellbeing Profile of … Glasgow Centre for Population Health. 2008
Health service provision
GP Practices, Community pharmacies, Palliative Care Network Pharmacies: [http://www.chps.org.uk/content/](http://www.chps.org.uk/content/) and related websites
Palliative care beds: Small Area Population Estimates (SAPE) General Register Office for Scotland (GROS)
Section 2: CH(C)P Practitioner Feedback on Palliative Care Services

CH(C)P Name: South West Glasgow

Method
Questionnaires were designed and piloted for Community Pharmacies and General Practices. These questionnaires were then completed for each setting as detailed below, analysed and key findings summarised by the newly appointed CH(C)P Macmillan Pharmacist Facilitator.

Community Pharmacy data collection
The Macmillan Pharmacist Facilitator visited all 31 (23 non-network, 8 network) Community Pharmacies between 2nd February and 8th April 2010. These visits were a mixture of pre-arranged and unarranged visits following a brief introduction to the Macmillan pharmacy project. The time spent in each pharmacy averaged 25 mins (range 20 – 40 mins). The 31 Pharmacists comprised 24 Managers; 3 Pharmacists; 4 locums.

General Practice data collection
An introductory letter, project poster and the questionnaire was distributed in April 2010 to all 26 General Practices requesting that a nominated GP complete the questionnaire for each practice. This process was supported by the CH(C)P Prescribing Support Team (PST) administrator who emailed all the practices and requested that returns be posted, faxed or emailed to the Macmillan facilitator. A total of 12 practices completed the questionnaire.

Separately the views of CH(C)P Practice Managers (PM) were captured through issue of the questionnaire to all PMs attending a CH(C)P PM meeting, attended by the Macmillan Pharmacist Facilitator June 2010. In September 2010, the facilitator attended a District Nurses’ meeting where 7 questionnaires were completed in addition to meeting a district nurse separately at the practice where another questionnaire was completed.

Key Findings
Table A and B present the responses to the core questions asked of Community Pharmacies and General Practices in South West CH(C)P. The key findings
identified by the Macmillan Pharmacist Facilitator on analysis of the data are summarised below:

**Community Pharmacy**

- Network knowledge – network pharmacies knew more than their non-network counterparts with regards to the network, medicines list and courier service however they had less knowledge of CD requisition forms and a similar knowledge of their nearest network pharmacy.
- There was support for palliative care training for support staff within Community Pharmacies however many were unsure of their roles in palliative care.
- Contact details of specialist palliative care Pharmacists and other members of the multidisciplinary palliative care team were available in only a few non-network Community Pharmacies.
- The most common sources of information utilised by Community Pharmacists included the BNF and Martindale however the internet was poorly utilised.

### Table A: South West Community Pharmacies responses to exploratory questionnaire (n=31)

<table>
<thead>
<tr>
<th></th>
<th>% Network Pharmacists (n=8)</th>
<th>% Non Network Pharmacists (n=23)</th>
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</thead>
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<tr>
<td><strong>Network Knowledge</strong></td>
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<tr>
<td>Pharmacy palliative care network</td>
<td>88</td>
<td>78</td>
</tr>
<tr>
<td>Nearest network pharmacy</td>
<td>63</td>
<td>61</td>
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<tr>
<td>The medicines list stocked by network pharmacy</td>
<td>88</td>
<td>48</td>
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<tr>
<td>Transport facility/protocol for medicines transfer</td>
<td>75</td>
<td>35</td>
</tr>
<tr>
<td>Awareness of CD requisition forms</td>
<td>50</td>
<td>57</td>
</tr>
<tr>
<td><strong>Sources of Information</strong></td>
<td></td>
<td></td>
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<tr>
<td>Specialist palliative care pharmacists</td>
<td>75</td>
<td>26</td>
</tr>
<tr>
<td>Contact details of the above</td>
<td>88</td>
<td>4</td>
</tr>
<tr>
<td>Contact details of other relevant members of multidisciplinary palliative care team</td>
<td>75</td>
<td>13</td>
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<tr>
<td><strong>Training</strong></td>
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<td></td>
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<td>Palliative care training in the last 3 years</td>
<td>63</td>
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<td>NES Palliative Care training completed</td>
<td>13</td>
<td>0</td>
</tr>
<tr>
<td>NES distance learning pack completed</td>
<td>25</td>
<td>13</td>
</tr>
<tr>
<td>Support of idea that technician/dispenser receives palliative care training</td>
<td>50</td>
<td>35</td>
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</table>
General Practices

- All Practice Managers had heard of the CP palliative care network however very few could identify their nearest network pharmacy
- 50% of GPs know of the CP palliative care network and 42% could identify their nearest network pharmacy
- Very few GPs have access to the network leaflet and knowledge of the medicines stocked by network pharmacies was very poor
- All have an updated palliative care register and 83% of GPs are happy to share information about these patients with their regular CP provided there is patient consent.
- One GP surgery feels there may be increased paperwork with sharing information with their CP
- Majority of District Nurses were able to identify their nearest network pharmacy however very few had a copy of the network leaflet

Table B: South West General Practices responses to exploratory questionnaires (n=19 questionnaires)

<table>
<thead>
<tr>
<th>Network Knowledge</th>
<th>% General Practitioners (n = 12)</th>
<th>% Practice Managers (n = 7)</th>
<th>% District Nurses (n = 8)</th>
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</thead>
<tbody>
<tr>
<td>Community Pharmacy palliative care network</td>
<td>50</td>
<td>100</td>
<td>75</td>
</tr>
<tr>
<td>Nearest network pharmacy</td>
<td>42</td>
<td>14</td>
<td>88</td>
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<tr>
<td>The medicines list stocked by network pharmacy</td>
<td>33</td>
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<td>50</td>
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<tr>
<td>Copy of network leaflet</td>
<td>33</td>
<td>43</td>
<td>13</td>
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<tr>
<td>Access to the network leaflet (including on-line)</td>
<td>8</td>
<td>14</td>
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<table>
<thead>
<tr>
<th>Palliative Care Services</th>
<th>n</th>
<th>% General Practitioners (n = 12)</th>
<th>% Practice Managers (n = 7)</th>
<th>% District Nurses (n = 8)</th>
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</thead>
<tbody>
<tr>
<td>Participation with Gold Standards Framework</td>
<td>83</td>
<td>100</td>
<td>88</td>
<td></td>
</tr>
<tr>
<td>Updated Palliative care register</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>Inclusion of non-cancer patients on Palliative care register</td>
<td>92</td>
<td>71</td>
<td>75</td>
<td></td>
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<tr>
<td>Staff trained to carry out Liverpool Care Pathway</td>
<td>8</td>
<td>14</td>
<td>75</td>
<td></td>
</tr>
<tr>
<td>Support of idea to share information about these patients with their regular community pharmacist provided there is patient consent</td>
<td>83</td>
<td>71</td>
<td>63</td>
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<tr>
<td>Regular Palliative Care Multidisciplinary Team meetings</td>
<td>100</td>
<td>100</td>
<td>88</td>
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Section 1: Population and Service Overview

Demography

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<tr>
<th>Description</th>
<th>Inverclyde</th>
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<tr>
<td>CHP Population (total number)</td>
<td>81,540</td>
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<td>Elderly population (aged 65+) [%]</td>
<td>17.3</td>
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<td>Minority ethnic groups [%]</td>
<td>0.9</td>
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<tr>
<td>Cancer patient registrants (mean annual number)</td>
<td>517</td>
</tr>
<tr>
<td>Cancer deaths (average annual rate 2003-2007)</td>
<td>271</td>
</tr>
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</table>

Health Service Provision

<table>
<thead>
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<th>Description</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Number of GP Practices</td>
<td>16</td>
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<tr>
<td>Number of GPs</td>
<td>66</td>
</tr>
<tr>
<td>Number of Community Pharmacies</td>
<td>19</td>
</tr>
<tr>
<td>• Independents (n≤4)</td>
<td>12</td>
</tr>
<tr>
<td>• Chains (n≥5)</td>
<td>7</td>
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<tr>
<td>Palliative Care Network Pharmacies</td>
<td>4</td>
</tr>
<tr>
<td>• Independents (n≤4 sites)</td>
<td>4</td>
</tr>
<tr>
<td>• Chains (n≥5 sites)</td>
<td>0</td>
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<tr>
<td>Nurses (DN, Practice Nurses)</td>
<td>125</td>
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<tr>
<td>Specialist Palliative Care Services</td>
<td>*</td>
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<tr>
<td>CHP Living and Dying Well Action Plan</td>
<td>yes</td>
</tr>
<tr>
<td>CHP multidisciplinary team Palliative care network</td>
<td>yes</td>
</tr>
</tbody>
</table>

* CHP has access to palliative care beds and specialists

Reference materials sourced to complete CHP profile Demography

A Community Health and Wellbeing Profile of … Glasgow Centre for Population Health. 2008
Health service provision
GP Practices, Community Pharmacies, Palliative Care Network Pharmacies: [http://www.chps.org.uk/content/](http://www.chps.org.uk/content/) and related websites
Palliative care beds: Small Area Population Estimates (SAPE) General Register Office for Scotland (GROS)
Section 2: CHP Practitioner Feedback on Palliative Care Services

CHP Name: Inverclyde

Method
Questionnaires were designed and piloted for Community Pharmacies and General Practices. These questionnaires were then completed for each setting as detailed below, analysed and key findings summarised by the newly appointed CHP Macmillan Pharmacist Facilitator.

Community Pharmacy data collection
The Macmillan Pharmacist Facilitator visited all 19 (15 non-network, 4 network) Community Pharmacies between 18th March to 4th May 2010. These visits were unarranged visits. The time spent in each pharmacy averaged 25mins (range 15 – 40minutes). The 19 Pharmacists comprised 15 Managers; 4 locums.

General Practice data collection
An introductory letter, project poster and questionnaire was distributed in April 2010 to all 16 General Practices requesting that all GPs and Practice Managers separately complete the questionnaire. This process was supported by the CHP Prescribing Support Pharmacists (PSP) who distributed the questionnaires to their practices with returns either directed to the PSP or posted direct to the Macmillan Pharmacist Facilitator. From the 14 (81%) of General Practices which responded a total of 47 questionnaires were analysed comprising 37 GP’s and 10 PM’s.

Key Findings
Table A and B present the responses to the core questions asked of Community Pharmacies and General Practices in Inverclyde CHP. The key findings identified by the Macmillan Pharmacist Facilitator on analysis of the data are summarised below:
Community Pharmacy

- Almost all reported an aspect of guessing that the person was in the palliative care stage of their life, some based that simply on the drug, others on seeing the person deteriorate over time and having knowledge of their condition.
- Only two thirds of Pharmacists knew about the network, with even fewer reporting that they have used or referred patients to the network. All non-network pharmacies asked for a summary or flow chart of the key points of the service that could be kept on or in the CD Cabinet.
- Network pharmacies seemed more likely to prioritise the dispensing of controlled drugs. With respect to the prioritisation of CDs all made a demarcation between perceptions of what is urgent or not based on prescriptions hand in or collection service and the urgency communicated by that person at the time.
- One non-network Pharmacist reported that the GPs often phones in advance to check that they have the item/s in stock.

Table A: Inverclyde Community Pharmacy responses to exploratory questionnaire (n=19)

<table>
<thead>
<tr>
<th></th>
<th>% Network Pharmacists (n = 4)</th>
<th>% Non Network Pharmacists (n = 15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Network Knowledge</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pharmacy palliative care network</td>
<td>100</td>
<td>67</td>
</tr>
<tr>
<td>Nearest network pharmacy</td>
<td>100</td>
<td>73</td>
</tr>
<tr>
<td>The medicines list stocked by network pharmacy</td>
<td>100</td>
<td>47</td>
</tr>
<tr>
<td>Transport facility/protocol for medicines transfer</td>
<td>100</td>
<td>67</td>
</tr>
<tr>
<td>Awareness of CD requisition forms</td>
<td>75</td>
<td>40</td>
</tr>
<tr>
<td><strong>Sources of Information</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Specialist palliative care pharmacists</td>
<td>100</td>
<td>73</td>
</tr>
<tr>
<td>Contact details of the above</td>
<td>100</td>
<td>46</td>
</tr>
<tr>
<td>Contact details of other relevant members of multidisciplinary palliative care team (at least one)</td>
<td>50</td>
<td>46</td>
</tr>
<tr>
<td><strong>Training</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative care training in the last 3 years</td>
<td>100</td>
<td>27</td>
</tr>
<tr>
<td>NES Palliative Care training completed</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>NES distance learning pack completed</td>
<td>100</td>
<td>13</td>
</tr>
<tr>
<td>Support of idea that technician/dispenser receives palliative care training</td>
<td>75</td>
<td>87</td>
</tr>
</tbody>
</table>

n/a – not asked
General Practices

- There is very little awareness of the network amongst GPs.
- Although the vast majority of GPs reported that they would phone the pharmacist in advance if they thought the medication was urgent only one pharmacist reported that the GPs did this.
- The vast majority of GPs would be happy to speak to the pharmacist about an apparent high dose. This fact will be helpful for Pharmacists, some of whom reported that it is difficult to do this.
- All of the GPs, with patient consent, would be happy to share relevant information with the person’s regular community pharmacist. …. How this is best done requires further exploration.
- No Practice Managers were aware of the network.

Table B: Inverclyde General Practice responses to exploratory questionnaires (n=47 questionnaires)

<table>
<thead>
<tr>
<th>Network Knowledge</th>
<th>% General Practitioners (n = 37)</th>
<th>% Practice Managers (n = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Pharmacy palliative care network</td>
<td>16</td>
<td>n/a</td>
</tr>
<tr>
<td>Nearest network pharmacy</td>
<td>8</td>
<td>n/a</td>
</tr>
<tr>
<td>The medicines list stocked by network pharmacy</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Copy of network leaflet</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>Access to the network leaflet (including on-line)</td>
<td>3</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Palliative Care Services</th>
<th>% General Practitioners (n = 37)</th>
<th>% Practice Managers (n = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participation with Gold Standards Framework</td>
<td>90</td>
<td>80</td>
</tr>
<tr>
<td>Updated Palliative care register</td>
<td>90</td>
<td>90</td>
</tr>
<tr>
<td>Inclusion of non-cancer patients on Palliative care register</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Staff trained to carry out Liverpool Care Pathway</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Support of idea to share information about these patients with their regular community pharmacist provided there is patient consent</td>
<td>100</td>
<td>n/a</td>
</tr>
<tr>
<td>Regular Palliative Care Multidisciplinary Team meetings</td>
<td>90</td>
<td>90</td>
</tr>
</tbody>
</table>

n/a – not asked
8 Conclusion

The Scottish Government national action plan “Living and Dying Well in Scotland”, was published in October 2008. The plan sets out a single, cohesive and nationwide approach to ensure the consistent, appropriate and equitable delivery of high quality and person-centred palliative care (based on neither diagnosis nor prognosis but on patient and carer needs). Within NHS GG&C the key platform for embedding this national plan has been the NHS GG&C Living and Dying Well Action Plan which has been informed by the NHS GG&C Palliative Care Health Needs Assessment, published in 2010 and the earlier NHS GG&C Pharmaceutical Palliative Care Health Needs Assessment from which this Macmillan project was established. The following outlines the existing good practice, current challenges and potential future direction:

8.1 Existing Good Practice

- Adoption of the Gold Standards Framework and use of the palliative care register with increasing inclusion of non cancer patients on this register, both viewed as driving improvements, particularly in anticipatory care and equity of care.
- Pharmacists engaged in the Community Pharmacy Palliative Care Network identified clear benefits of being part of the network including: agreement of a core medicines list to facilitate rapid supply; access to training and opportunity to discuss clinical practice; connection to specialist advice and the local multidisciplinary team.
- Good relationships between District Nurses and Community Pharmacies supporting service delivery through better understanding of patient needs and timely medicines supply.
- Professional Carers identified District Nurses and Community Pharmacists as accessible and approachable in their support of patients at home.
- Patients/Family Carers praised the support of their Professional Carers and District Nurses in particular, and the connections they have to other health care professionals.
8.2 Challenges

Effective engagement and communication between health care professionals, with patients and across care settings, in particular:

- Transfer between hospital and home remains problematic, particularly in regard to variability of information (including GP notification) and medicines/equipment supplied, especially with a Friday discharge.
- Communication between General Practitioners and Community Pharmacists is variable.
- Local engagement and support between network and non-network pharmacies is variable.
- Lack of information / continuity of information for health care professionals and patients, particularly if changing pharmacy to access palliative care medicines.

Limited prescriber awareness of the medicines list held in Network Pharmacies to support rapid access and evidence of significant issues with controlled drug prescribing meeting legal requirements to enable medicine supply.

Several aspects of the medicines supply process remain challenging within the Community Pharmacy setting. These are:

- Identification of palliative care/urgent prescriptions.
- Incomplete dispensing of prescriptions causing inconvenience to carers.
- Difficulties around collection of prescriptions by carers/health care professionals.
- Continuation of medicines supply, in particular relating to monitored dosage systems in circumstances such as hospitalisation or death.
- Ready access to information sources on medicines, including unlicensed medicines, to support patient care for both patients and health care professionals.

Out of hours/weekend services may be compromised through:

- Lack of continuity of service provision in the Community Pharmacy Palliative Care Network at weekends.
• Limited access to specialist advice.
• Minimal or no clinical information transfer to out of hours/weekend services to support patient care and supply of medicines.

Variability in level of service provision reported by patients/family carers from excellent joined up service to disjointed service with particular reference to:
• Challenges and anxieties for carers, particularly sole carers, when required to leave patients to manage logistics across the Primary Care Team.
• Co-ordination of health professional visits within the home setting to avoid patient/carers being inundated.
• Difficulties in communicating effectively patients’ prognosis to patients/family carers.

8.3 Future Direction

The evaluation provides an evidence base to inform and shape activities within the NHS GG&C Palliative Care Managed Clinical Network. In particular it will support the development of an action plan to enhance the effectiveness of the Community Pharmacy Palliative Care Network (CPPCN) to support all pharmacies to deliver palliative care within and across the study CH(C)Ps and provide a focus for the evolving role of the Macmillan Pharmacist Facilitator. Key areas for consideration are:

Support for practitioners engaged in palliative care including consideration of the following:
• Tools to aid practitioners with selection, and the legal requirements for prescribing and monitoring of medicines in palliative care.
• Accessible information for all service providers and patients/carers on how to access medicines 24/7.
• Access to information resources about medicines used in palliative care.
• Clinical information transfer between care settings and to out of hours / weekends service providers to provide relevant and up to date patient care plans. This information could potentially be deployed through the evolving electronic palliative care summary (ePCS).
• Developing skills in preparing for difficult conversations with Patients/Family Carers on prognosis and anticipation of death. This could be implemented as part of the current strategy focused on palliative and end of life care including DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation).

• Introduction of the “Just In Case” box within patients home being rolled out across CH(C)Ps.

Improved communication between General Practitioners, District Nurses and Community Pharmacists to support co-ordination and continuity of care through:

• Improved CPPCN awareness.

• Multidisciplinary training/clinical review sessions to support networking to share good practice.

• Sharing information about palliative care patients on the GP register with the patients’ community pharmacist with patients’ consent. This should be supported through application of the NHS GG&C Information Sharing Strategy to the palliative care setting.

Continued integration of the CPPCN within the broader Community Pharmacy Network including:

• Communication with and training of pharmacist locums / non network pharmacies on key components of the network.

• Training of dispensing/technician staff/counter assistants to support engagement with carers/health care professionals in the Community Pharmacy to improve medicines supply and patient/carer support.
References


[37] Culyer A. Need--is a consensus possible? J Med Ethics 1998; 24: 77-80


[51] Ellershaw J, Ward C. Care of the dying patient: the last hours or days of life. BMJ 2003; 326: 30-4


