Macmillan Pharmacist Facilitator Project

Final Evaluation Report – 2012
This report presents work undertaken as a collaboration between the NHS Greater Glasgow and Clyde, Macmillan Pharmacist Facilitator Project Team and the Strathclyde Institute of Pharmacy and Biomedical Sciences, University of Strathclyde.

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**Acknowledgements**

**Macmillan Cancer Support for the Project funding**

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Scottish Partnership for Palliative Care
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Executive Summary

Introduction

The Healthcare Quality Strategy provides a direction of travel for NHS Scotland. This is contextualised for palliative care through the national action plan “Living and Dying Well in Scotland” which sets out a single, cohesive and nationwide approach to ensure the consistent, appropriate and equitable delivery of high quality and person-centred palliative care.

A health needs assessment in pharmaceutical palliative care was conducted in the former NHS Argyll & Clyde area and identified gaps in service delivery which were considered pertinent to the new NHS Greater Glasgow & Clyde Health Board area. Subsequently, Macmillan Cancer Support agreed to fund a three year project (2009 – 2012) to address these gaps in practice and explore a new service delivery model of community pharmacy palliative care services. An integral part of the work programme was the establishment of Macmillan Pharmacist Facilitator posts in four community health and social care partnerships (CH(C)Ps), to support and improve pharmacy services.

The University of Strathclyde were commissioned to support the development and evaluation of this new service. This document reports on the first two years of project activity (2010 – 2011).

Aim

To inform the development of the Macmillan Pharmacist Facilitator role in delivering a quality improvement programme of patient care services provided by community pharmacists in the NHS GG&C.

Methods

The project comprised of three key phases of work.

Phase 1: Aimed to characterise current (baseline) community pharmacy services in the four project CH(C)Ps, and identify key issues and gaps in current practice through qualitative and quantitative methods. Data were derived from group and face-to-face interviews with healthcare professionals, professional carers, patients and their carers.
A questionnaire was also circulated to pharmacists, practice managers, district nurses and GPs.

Phase 2: The findings of Phase 1 informed the development of a quality improvement programme, focussed on community pharmacy palliative care services but supporting the wider multidisciplinary team, that was implemented across the four project CH(C)Ps.

Phase 3: The resultant interventions and activities implemented as part of the quality improvement programme were analysed to inform an evidence-based model for community pharmacy services in palliative care.

Results
Phase 1 identified a range of existing good practices in pharmacy service delivery, supporting the needs of palliative care patients and members of the community health care team. A number of gaps were identified including: variable communication between health care professionals, and across health care settings; a lack of concise and up-to-date palliative care resources and information for health professionals and patients; and a lack of knowledge regarding the prescription and supply of palliative care medicines. Opportunities for educating pharmacy staff, both pharmacists and support staff, were also identified. See Baseline Report for further details http://www.palliativecareggc.org.uk/uploads/file/guidelines/Macmillan%20Exec%20Summary%20FINAL%202_.pdf

Phase 2 focused on three key areas of activity: information resources; communication / networking strategies and skills development. This resulted in the generation of a number of tools: to assist needs assessment and resources to improve service delivery; and support education and training of pharmacy teams and the wider multidisciplinary team in the safe and effective use of medicines. (see table). Several of the resources generated have been disseminated more widely than the original four CH(C)Ps both across NHS GG&C and the wider NHS in Scotland.
Table – Tools and Resources developed through project delivery

<table>
<thead>
<tr>
<th>Information Resources</th>
<th>Communicating and networking strategies</th>
<th>Skills development</th>
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<tbody>
<tr>
<td><strong>Resources</strong></td>
<td><strong>Tools</strong></td>
<td><strong>Resources</strong></td>
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<tr>
<td>• Palliative care resource folder</td>
<td>• Communications Development exercise form</td>
<td>• Palliative care Pharmaceutical Care Plan</td>
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<tr>
<td>• Prescribing prompts</td>
<td>• Facilitator diary/activity log</td>
<td>• Palliative care Pharmacist education programme.</td>
</tr>
<tr>
<td>- Palliative care</td>
<td>• Mapping of common pharmacy / MDT networks and events.</td>
<td>• Palliative care Pharmacy support staff education programme.</td>
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<tr>
<td>Prescribing Aid</td>
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<tr>
<td>- Levomepromazine</td>
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<td>information card</td>
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Phase 3
Observation and capture of project activity over the initial 2 years of the project has enabled a detailed analysis of community pharmacy clinical practice in support of palliative care to be undertaken. This has informed the construction of a model identifying three key functions that are viewed as important to the delivery of effective pharmaceutical palliative care services within a primary care setting: community pharmacy; interface/facilitator; leadership and team co-ordination/administrative function, and sets these within the current palliative care framework for NHS Scotland. Through mapping the key roles for these functions a capacity planning model has been developed for pharmacy palliative care services in primary care, an area where there is currently no published work.

Conclusion
For NHS Scotland this evidence presents for the first time a conceptualised clinical practice model and capacity planning framework for community pharmacy palliative care services. This model is focused on aligning with policy frameworks in pharmacy to maximise the use of pharmacists’ professional competence in planning and delivering clinical services. The model provides detail of the key functions and activities important
to support the safe and effective use of medicines for patients and their carers but provides this in a format that enables flexibility for the deployment of these functions through local business planning and service delivery frameworks.
<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>CDs</td>
<td>Controlled Drugs</td>
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<tr>
<td>CH(C)P</td>
<td>Community Health (and Care) Partnerships</td>
</tr>
<tr>
<td>CMS</td>
<td>Chronic Medication Service</td>
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<tr>
<td>CPD</td>
<td>Continuing Professional Development</td>
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<td>CPDT</td>
<td>Community Pharmacy Development Team</td>
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<td>CPPCN</td>
<td>Community Pharmacy Palliative Care Network</td>
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<tr>
<td>ePCS</td>
<td>Electronic Palliative Care Summary</td>
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<td>GSF</td>
<td>Gold Standard Framework</td>
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<tr>
<td>GSFS</td>
<td>Gold Standard Framework Scotland</td>
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<tr>
<td>LCP</td>
<td>Liverpool Care Pathway</td>
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<td>LMC</td>
<td>Local Medical Committee</td>
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<tr>
<td>MDT</td>
<td>Multidisciplinary Team</td>
</tr>
<tr>
<td>NES</td>
<td>NHS Education for Scotland</td>
</tr>
<tr>
<td>NHS GG&amp;C</td>
<td>NHS Greater Glasgow and Clyde</td>
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<tr>
<td>PCP</td>
<td>Pharmaceutical Care Plan</td>
</tr>
<tr>
<td>PCPMG</td>
<td>Primary Care Prescribing Management Group</td>
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<tr>
<td>PIL</td>
<td>Patient Information Leaflet</td>
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<tr>
<td>PRISMS</td>
<td>Prescribing Information System for Scotland</td>
</tr>
<tr>
<td>PPSU</td>
<td>Pharmacy and Prescribing Support Unit</td>
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<tr>
<td>REC</td>
<td>Research Ethics Committee</td>
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<td>SPCC</td>
<td>Scottish Partnership for Palliative Care</td>
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<td>SPCPA</td>
<td>Scottish Palliative Care Pharmacist Association</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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Purpose of the report
The purpose of this document is to report on the first two years’ activity of the Macmillan Pharmacist Facilitator project (Jan 2010 – Dec 2011).

Project activity during this time period has been divided into three phases.

Phase 1
A baseline report was produced in 2010, focusing on the first six months of project activity (Jan 2010– June 2010), specifically the investigations to characterise current community pharmacy palliative care services in the study Community Health (and Care) Partnerships (CH(C)Ps) and the identification of service gaps and key issues to inform a quality improvement programme. This report includes a summary of the Phase 1 project activity, for which a separate full report is available.

Phase 2
Findings of Phase 1 provided the framework for the following 18 months of project activity. This report presents the collation of project activity up to and including December 2011.

Phase 3
Phase 3 presents a proposal for an evidence-based service model for community pharmacy palliative care services.

Background
Palliative care is defined by the World Health Organization (WHO) 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 is at present most commonly provided to cancer patients, with 90% of specialist palliative care services in Scotland provided to cancer patients [2]. However, long term conditions such as heart failure, COPD and dementia account for around 60%
of all deaths [3]. Consequently it is now generally accepted that people living with serious chronic illnesses will require palliative care and thus palliative care should be offered more widely and integrated more broadly across the health care services [4,5].

Palliative Care Policy Framework in Scotland

In August 2008, Audit Scotland published a ‘Review of Palliative Care Services in Scotland’, stating that there was currently no coordinated national strategy for palliative care [2]. Taking into account the recommendations of the above report, the Scottish Government launched ‘Living and Dying Well: A national action plan for palliative and end of life care in Scotland’ [6]. ‘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 patient and carer needs. The Action Plan states that NHS Boards and 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 (MDT). A number of established good practice frameworks are in the Action Plan including the Gold Standards Framework (GSF) and the Liverpool Care Pathway (LCP).

The GSF is a systematic approach to support primary care teams to improve the organisation and quality of care for patients nearing the end of life in the community. A modified Scottish version of the GSF, the GSF Scotland (GSFS), was introduced in 2003. As of 2009, 80% of GP practices in NHS Greater Glasgow and Clyde (GG&C) were signed up to the GSFS [7]. The LCP is an evidence-based framework providing guidance on the different aspects of care required, including comfort measures, anticipatory prescribing, discontinuation of inappropriate interventions and bereavement care. In Scotland the LCP is currently used in 12 of the 13 hospices. However, in 2008 only a quarter of district nurses reported that they were currently using the LCP [2]. In 2010 NHS GG&C identified that 37% of GP practices, 33% of nursing homes and 47% of hospital wards in the acute operating division reported using or were in the process of implementing the LCP [7].

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, proposing a better use of pharmacists’ professional competence in planning and delivering services, especially in priority areas such as cancer, heart disease and mental health [8]. This document placed an 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 has resulted in most NHS Boards establishing Community Pharmacy Palliative Care Networks (CPPCN). Access to specific palliative care medicines within and out-with working hours is a quality standard in all NHS Board areas [9].

**Current Palliative Care Services**

Within the WHO European region, the UK has one of the highest ratios of palliative care services to population, the highest level of development of specialised palliative care teams and one of the highest ratios of specific palliative care beds to population [10,11]. In Scotland, specialist care is available through a range of settings including hospital, hospice and in the home via home care teams. Despite the range of services, gaps in palliative care service provision and significant variation in the quality of care across Scotland are still reported [2,12].

A Palliative Care Health Needs Assessment conducted in NHS GG&C was published in 2010 in response to the Living and Dying Well Action Plan. The Health Needs Assessment recognised community nursing services, general medical practice, pharmacy services and specialist palliative medicine as areas 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 lack of 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 were essential factors in enabling patients to stay at home, hence avoiding admissions to hospital [7].

A palliative care Pharmaceutical Health Needs Assessment was conducted across the then NHS Argyll and Clyde area from 2005 – 2007, using the ‘Toolkit for assessing the
pharmaceutical needs of populations: Palliative care pharmaceutical services’[13, 14]. The Pharmaceutical Health Needs Assessment identified that the majority of CPPCN pharmacies had the agreed stock of palliative care medicines. However, problems in obtaining urgently required palliative care medicines resulted from an earlier failure to anticipate changing needs of patients, such as the inability to take oral medicines. Further difficulties were identified relating to 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 (CDs) and palliative care medicine out-of-hours still occurred. Issues in accessing unlicensed medicines, including uncertainties regarding how to prescribe or obtain them, were also identified.

The Pharmaceutical Health Needs Assessment demonstrated that good practice had to become more widespread and awareness of the CPPCN be increased. Recommendations included: regular training and multi-disciplinary peer review meetings; provision of induction training for new pharmacists joining the CPPCN; attendance of community pharmacists at GP practice GSF meetings, resulting in the notification of the palliative care status of individual patients becoming routine; and the transfer of pharmaceutical care issues between different care sectors.

**Macmillan Project**

Building on the Health Needs Assessments, NHS GG&C sought funding from Macmillan Cancer Support to address recommendations of the Pharmaceutical 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. In 2009 Macmillan Cancer Support agreed to fund a 3 year project (November 2009 – October 2012) which would pilot the establishment of 4 Macmillan Pharmacist Facilitators (each 0.2WTE), located in 4 CH(C)Ps across the NHS GG&C area, 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 the CPPCN, ensuring opportunities are developed for training and peer support and providing quality information to support practice.

The project has been delivered by the NHS GG&C Macmillan Pharmacist Facilitator Project Team which comprised the Project lead, Project administrator and the four appointed CH(C)Ps Macmillan Pharmacist Facilitators. In addition the project is supported by two key groups:

**Project Steering Group:** comprising NHS management and project team representatives, funding body, and University representatives.

**Project Evaluation Group:** comprising NHS service representatives / University and NHS Project Team representatives, funding body.

**Ethical Approval**

The University of Strathclyde was commissioned to support the development and evaluation of this new service. The University Code of Practice on Investigations Involving Human Beings was found to not apply to this project since it was an audit of an existing service/practice.

Additionally, under the terms of the Governance Arrangements for NHS Research Ethics Committees (REC) in the UK, the project did not meet the requirements for ethical review because it was intrinsically development of an existing service, and participation into any empirical research components, i.e. Focus Groups, was by invitation only. In addition:

• The transcripts from interviews and focus groups would be irreversibly anonymised so that the respondent’s identity was fully protected.

• It is also not possible to identify any individual from any direct quotation used in the reporting of the project.
**NHS Greater Glasgow & Clyde**

NHS GG&C is the largest of 14 geographical NHS Boards in Scotland. NHS GG&C has a population of 1,116,040 (2010) 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.[16] At the time of commencing the Macmillan project there were 10 CHPs in NHS GG&C. There were a total of 313 community pharmacies within NHS GG&C, with 71 of these members of the CPPCN.

The four CH(C)Ps selected for the Macmillan project were the South West Glasgow CHCP; West Glasgow CHCP; West Dunbartonshire CHP; and the Inverclyde CHP, covering a total population of approximately 430,000 people, and comprised 112 community pharmacies, of which, 26 were members of the CPPCN. In early 2011 five CH(C)Ps from NHS GG&C, including South West Glasgow CHCP and West Glasgow CHCP, were merged to form the Glasgow City CHP. However, the Macmillan Pharmacist Facilitators continued to largely work within the former CH(C)P areas.
1. Phase 1: Baseline study

Aim:
To characterise the current community pharmacy service in the project study CH(C)Ps and to identify service gaps and key issues to inform a quality improvement programme

Methods:
A mixed methods study, using a qualitative and quantitative approach, was adopted.

Qualitative study
Group and face-to-face interviews were conducted by members of the university team to explore the views of health care professionals, professional carers and patients/carers on current pharmacy service provision and areas for improvement. Brief interview schedules were developed based on the study objectives. All interviews were audio-recorded, transcribed verbatim and analysed using the Framework Approach.

Quantitative study
Questionnaires completed by community pharmacies and general practices in the project CH(C)Ps were used to collect exploratory baseline data on: knowledge of the 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.

Results:
Key findings of Phase 1 are provided below. Please refer to the baseline report for the full results:

Qualitative study
Data collection was undertaken between January and July 2010 in the four CH(C)Ps.
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.

Quantitative study
Questionnaires were completed by: 85% (n=23) of network pharmacies, 93% (n=80) of the non-network pharmacies, 51% (n=55) of the practice managers, and 23% (n=91) of the general practitioners. A standard profile was prepared for each CH(C)P and comprised: population and service overview; CH(C)P 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>
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</thead>
<tbody>
<tr>
<td><strong>Patients and Family Carers</strong></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>&quot;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>Communication</td>
<td>&quot;..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></td>
<td>&quot;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>Other issues</td>
<td>&quot;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></td>
<td>[NHS24 is] &quot;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&quot;</td>
</tr>
<tr>
<td><strong>Palliative Care Network Pharmacists</strong></td>
<td>The Community Pharmacy Network</td>
<td>&quot;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>&quot;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>The Dispensing of Palliative Care Medicines</td>
<td>&quot;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 it if you’ve got clarification over the phone.”</td>
<td></td>
<td>&quot;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>Sources of Information</td>
<td>&quot;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></td>
<td>&quot;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>
<tr>
<td>Participants</td>
<td>Theme identified</td>
<td>Strengths of current service provision</td>
<td>Issues &amp; gaps of current service provision</td>
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<td>Training and Education</td>
<td>&quot;Most of my counter staff are able to recognise unusual stuff... they are able to recognise most controlled drugs now.&quot;</td>
<td>&quot;...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.&quot;</td>
<td></td>
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<tr>
<td>Communication</td>
<td>“[District Nurses] can also sort [incorrect prescriptions], 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.”</td>
<td>“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.”</td>
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<tr>
<td>District Nurses, General Practitioners, Professional Carers</td>
<td>Palliative care services in General</td>
<td>“...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.” [District Nurse]</td>
<td>“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.” [GP]</td>
</tr>
<tr>
<td>Pharmacy Services</td>
<td>“…we’ve got a good relationship with the pharmacists.” [District Nurse]</td>
<td>“I was due to finish at 12.30 and I went down there to community pharmacy at 12.20 and I was still standing there at 12.55 to get the prescription to take back to the patient.” [District Nurse]</td>
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<tr>
<td>Communication</td>
<td>“...but most primary care teams are reasonably, in my experience, reasonably unified and cooperative in a professional sense.” [GP]</td>
<td>“… 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.” [GP]</td>
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<tr>
<td>Out-of-Hours Issues</td>
<td>“My impression is that [out of hours is] better organised than we ever were when we were just doing our extended rota.” [GP]</td>
<td>“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 …” [District Nurse]</td>
<td></td>
</tr>
</tbody>
</table>
Table 2: Selected responses to questionnaires distributed within the four project 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>

^The lowest and highest responses from the project CH(C)Ps
*Question not asked
Conclusion:
Phase 1 identified a range of existing good practices, which supported the needs of palliative care patients and their carers in the community, as well as members of the health care team. These included:

- Adoption of the GSF and use of the palliative care register with increasing inclusion of non-cancer patients on the register were both viewed as driving improvements, particularly in anticipatory care and equity of care
- Pharmacists engaged in the CPPCN 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 were identified, 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/carers praised the support of their professional carers and district nurses in particular, and the connections they have to other health care professionals.

A number of challenges in the delivery of effective community pharmacy palliative care were also identified. These challenges represented opportunities for the Macmillan Pharmacist Facilitators to support and oversee service improvement through targeted interventions and educational strategies. Table 3 summarises the challenges and suggested interventions and strategies to improve current services, grouped under three key themes: Communication and engagement; Knowledge and skills; and Pharmacy service provision.

The suggested interventions to close the gaps in current practice provided the framework for Phase 2 of the project, informing a quality improvement programme to be implemented by the Macmillan Pharmacist Facilitators across the 4 CH(C)Ps and where feasible, across NHS GG&C. Engagement with existing teams was required to assist the implementation of some of the suggested interventions.
### Table 3: Challenges and suggested interventions

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Suggested interventions</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Communication and Engagement</strong></td>
<td></td>
</tr>
<tr>
<td>Poor transfer of information between hospital and the community</td>
<td>• Improve information sharing between care settings (e.g. Immediate Discharge Letter from the hospital and an equivalent from the hospice setting)</td>
</tr>
<tr>
<td>Variable communication between GPs, pharmacists and district nurses</td>
<td>• Sharing of information regarding palliative care patients on the GP register, supported by the NHS GG&amp;C Information Sharing Strategy  &lt;br&gt; • Sharing of information between care settings via the electronic palliative care summary (ePCS)  &lt;br&gt; • Promote a multidisciplinary approach towards pharmacy education/training  &lt;br&gt; • Pharmacy involvement in multidisciplinary review sessions  &lt;br&gt; • Raise awareness of out-of-hours contacts (e.g. district nurses)</td>
</tr>
<tr>
<td>Variable communication between network and non-network pharmacies</td>
<td>• Promote communication and information sharing between network and non-network pharmacies  &lt;br&gt; • Highlight the role of network pharmacies as a resource</td>
</tr>
<tr>
<td><strong>Knowledge and skills</strong></td>
<td></td>
</tr>
<tr>
<td>Lack of awareness of CPCCN</td>
<td>• Engagement with locum and non-network pharmacists regarding the CPPCN  &lt;br&gt; • Attendance at Locality Palliative Care Groups, GP forums and other relevant multidisciplinary team meetings</td>
</tr>
<tr>
<td>Varied access to accurate and up-to-date information about palliative care medicines for health professionals</td>
<td>• Raise awareness of current palliative care resources available for GPs and district nurses  &lt;br&gt; • Development of a single resource for pharmacists including current palliative care resources</td>
</tr>
<tr>
<td>Limited awareness of palliative care medicines list and legal requirements to prescribe Controlled Drugs</td>
<td>• Develop tools to aid practitioners with the selection of, and the legal requirements for prescribing, palliative care medicines  &lt;br&gt; • Add list of palliative care medicines to GP prescribing software</td>
</tr>
<tr>
<td>Lack of confidence in dealing with difficult conversations in the pharmacy</td>
<td>• Produce and deliver communication skills training materials for community pharmacists and support staff</td>
</tr>
<tr>
<td>Varied levels of confidence in providing symptom management advice</td>
<td>• Develop and implement a needs based education programme for pharmacists  &lt;br&gt; • Develop a clinical prompt and pharmaceutical care plan to support pharmacists</td>
</tr>
<tr>
<td><strong>Pharmacy Service Provision</strong></td>
<td></td>
</tr>
<tr>
<td>Challenges</td>
<td>Suggested interventions</td>
</tr>
<tr>
<td>----------------------------------------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| Lack of transfer of information between network and non-network pharmacies | - Development of a single resource for pharmacists including the contact details of local network pharmacies  
- Promote communication and information sharing between network and non-network pharmacies  
- Develop relationships with area managers of pharmacy multiples to raise awareness of the CPPCN and palliative care |
| Identifying and prioritising palliative care patients/prescriptions        | - Training and education of pharmacy support staff and relief/locum pharmacists          |
| Inadequate stock of medicines to fill prescriptions                        | - Training and education of pharmacy support staff                                      |
|                                                                             | - Develop a specialist palliative care stock and expiry checklist                      |
| Lack of continuity of service at weekends/out of hours                     | - Development of a single resource for pharmacists regarding provision of palliative care services  
- Training and education of pharmacy support staff and relief/locum pharmacists |
| Unsure how to access specialist advice, particularly out of hours/weekend  | - Development of a single resource for pharmacies including a list of contact details of local experts/units |
| Lack of patient and carer information                                       | - Ensure accessible information for patients and carers on how to access medicines 24/7  
- Develop a patient information section as part of the pharmacy resources  
- Promote pharmacy services to patients and carers  
- Supply pharmacies with leaflets promoting support services (e.g. Macmillan Cancer Support, Maggie's Cancer Caring Centres and Local Carer Support Services) |
2. Phase 2: Key areas for action

Aim:
To develop and implement a quality improvement programme, by incorporating key areas of action informed by the challenges and suggested interventions identified in Phase 1.

Methods:
The challenges identified in Phase 1 were analysed to identify a framework of key activities to help close gaps in current community pharmacy palliative care service provision. Key activities were then prioritised and implemented by the Macmillan Pharmacist Facilitators across the 4 CH(C)Ps during the 18 months of Phase 2 project activity.

Results:
The results for Phase 2 are divided into three discreet areas of action, each describing the range of resources and activities implemented to address the gaps identified in Phase 1. In addition there is a Project Team reflections and learning section and recommendations for consideration in planning year 3 of the project.

2.1 Information resources

2.1.1 Optimising the provision of information for patients

Phase 1 identified poor communication and a lack of information as key factors affecting the smooth delivery of palliative care services from community pharmacies. Communication was less than optimal between different health professionals, who were often unaware of each other’s roles and responsibilities. Patients and their carers were also found to have limited knowledge and awareness of the role of pharmacy in the overall delivery of community based palliative care services. Traditional means of information dissemination, such as leaflets or posters were considered as potential resources to address some of these concerns. However a more rapid and cost effective medium with potential for a wider impact, such as the Macmillan Cancer Support website (www.macmillan.org.uk/Home.aspx), was also identified as a potential
information giving resource.

During meetings with the Macmillan Project Steering Group, it became clear that Macmillan would be receptive to developing a pharmacy specific section on their main website. These pharmacy web pages would be used to inform patients and their carers of the nature of services provided by community pharmacies and the role of the pharmacist. These web pages were not to be the forum for accessing clinical information about medicines or treatments, yet they would contain practical information, for example, relating to the prescription dispensing process and access to/supply of certain medicines. It was envisaged that the information would be used by patients or their carers prior to a visit to their pharmacy and to inform them as to what to expect from their visit. The information would detail the range of services that could be accessed from community pharmacies.

To allow an evidence based approach to be applied towards the development of pharmacy pages on the Macmillan website, the health seeking behaviour of palliative care patients had to be investigated. Two approaches were used: a literature search to determine the nature of information required by patients (and their carers) and their preferred medium for dissemination of this information, and a qualitative study involving group interviews with patients and carers to explore their pharmacy specific information needs and how these could be addressed.

**Literature Review**

**Aim:**
To determine the health information seeking behaviour of palliative care patients and their carers.

**Method:**
Two medical (Medline, Embase) and one psychology (PsycInfo) databases were searched, using the following keywords: “Palliat$ Care”, “Palliat$ Med$”, “Medicine$ Information”, “Patient Information”, “Palliative Care” AND Information AND Patient$; “Patient Medic$” AND Information; Palliative AND Patient AND Information AND Online OR Internet OR e-health; Palliative AND “Patient Information” AND Internet; Palliative
AND Patient AND Information AND Leaflet; “Drug Information” AND Palliative; Medication AND Information AND Palliative; Palliative AND “Patient Information”.

Results:
One hundred and ninety abstracts were identified and reviewed and from these, 16 articles were retrieved. Four of the 16 articles were Systematic Reviews. The composition of the review articles and their relative timeliness meant that when these articles were consulted, they provided a thorough and efficient means for understanding the literature in this area. The findings from the 4 systematic reviews are summarised in Table 4.
### Table 4: Summary of systematic reviews

<table>
<thead>
<tr>
<th>Review Article</th>
<th>Key Points</th>
</tr>
</thead>
</table>
| 1. Kinnane & Milne (2010) [17] | • Younger, female carers with higher levels of education and socioeconomic backgrounds, with computer access in the home or at work, and who have direct care responsibilities are more likely to use the internet for cancer related information.  
• Patients with breast cancer appear to make most use of the internet out of all the cancers (but this may be a reflection of the greater number of web based resources aimed at breast cancer)  
• The Internet is primarily used for information about disease and treatment, Support Group activity and e-mail (to build and maintain relations with health professionals)  
• Carers are likely to use the internet if they have poor/little access to medical staff or if information is not forthcoming from the health professional.  
• Carers would prefer the health professional to advise on which sites to visit, i.e. make recommendations.  
• Information is generally sought about: the disease, treatment options, complementary or alternative therapies and nutrition.  
• The internet is seen as a convenient resource by those who have easy access to it, however, for many carers, it does not replace face to face contact or other forms of information dissemination. |
| 2. Docherty et al. (2008) [18] | • Caregivers report most concern and inadequate knowledge in pain management, especially the side effects of medicines, disease progression and addiction/tolerance.  
• Caregivers struggle with matters concerning the timing of medicines, particularly when to give ‘as required’ doses. They also underestimate the experience of breakthrough pain.  
• Little information available about the needs of ethnic groups; however black patients in the UK reported a greater sense of dissatisfaction with communication with health professionals than white patients.  
• Caregivers who are more knowledgeable about the condition and its treatment delivered better care.  
• Health professionals should provide opportunity for two way communication with the patient and their carer. |

(20 studies covering 8 yr period 02-09)  
(34 studies, 24 specific to carers of cancer patients)
3. **Finney, Rutten et al. (2005)** [19]  
(112 studies specific to patients’ needs)  
- Top Ten list of ‘information needs’ identified: 1. treatment related including treatment options, side effects, tests and procedures. 2. cancer-specific such as type of cancer, etiology and course. 3. rehabilitation. 4. prognosis such as cures, survival rates. 5. coping i.e. emotional support. 6. interpersonal/social such as risk of disease for family. 7. body image (sexuality). 8. surveillance i.e. prevention and early detection. 9. financial/legal. 10. medical system i.e. staff ability and quality of service.  
- Younger patients are more likely to seek information than older patients. Women more likely than men.  
- Older patients more receptive to information provided by physician.  
- Individuals in ↑ socioeconomic group consult ↑ range of resources.

The importance of information giving for patients newly diagnosed with cancer. J Clinical Nursing 8: 631-64.  
(16 studies examining provision of information by nurses)  
Four topics identified:  
- The ‘role of information’: informed patients have better treatment compliance and self-care as well as more realistic expectations of their treatment and prognosis.  
- ‘Factors influencing information seeking’: ↑ variability between studies and hence cancer type. No differences found between gender or educational achievement and desire for information.  
- ‘Methods for providing information’: Patients struggle with verbal information upon hearing of diagnosis. Written information should reinforce that which is provided verbally.  
- ‘Nature of Information’: Topics include; extent of the disease, likelihood of disease and prognosis, treatment effects on social activities, effect on family/friends, self-care and return to normal life, psychological effects of treatment, types of treatment available (pros/cons) and treatment side effects.
Qualitative Study

Aim:
To investigate the pharmacy specific information needs of patients and carers.

Methods:
A purposive sampling strategy was applied. Potential participants for the focus groups were identified from pre-existing patient / carer support groups meeting in the local areas. The Macmillan Pharmacist Facilitators and members of the project evaluation group in consultation with other professional colleagues / contacts (i.e. district nurses, hospice managers, GP practice managers and prescribing support staff), were tasked with finding suitable groupings or individuals to take part in the focus groups. The contacts were each provided with an information pack (detailing the study and the inclusion criteria for participant recruitment*), accompanied by an information leaflet which was to be given to potential participants. They were encouraged to approach eligible patients or family carers, explain the aim of the project and pass on contact details to the Macmillan Pharmacist Facilitators, if they consented. The Facilitators together with the university team arranged mutually convenient and suitable interview locations and times.

*Inclusion Criteria: Participants must be a patient receiving palliative care, or a carer (family or professional) who 'looked after' a palliative care patient. They also had to use/access a local Community Pharmacy and had to live within the project CHPs.

Data collection:
Semi-structured focus groups were conducted to primarily investigate patients’ and carers’ experiences of accessing information about their medicines, and of pharmacy services. An interview schedule was developed to determine the following:

- Who do participants ask for information about their medicines?
- What type of information do they receive and in which format?
- Do they receive additional information about their medicines or other services from their pharmacy / pharmacist?
- Would they like to receive information about their medicines and other services from their pharmacy / pharmacist?
- What else could be done by the pharmacy / pharmacist to make things easier for them (as patients / carers)?
All interviews were audio recorded and lasted between 30 and 60 minutes. The interviews were transcribed verbatim and analysed separately by two members of the university team. Since the earlier literature review had already identified the main topics for investigation, the resulting articulated data from the focus groups were subjected to a deductive content analysis [21].

Research ethics approval was considered unnecessary as this was an evaluation of current service and patient participation was voluntary and anonymous (as advised by the University Code of Practice on Investigations Involving Human Beings and the West of Scotland NHS Research Ethics Service).

Results:
A total of 27 participants, including 14 patients and 13 carers who interacted with community based palliative care services took part in the focus group interviews. The patients ranged in age from 65 – 79 years, whilst the carers were slightly younger, ranging from 57 – 74 years. A total of six group interviews were conducted. Each group contained a mixture of patients and carers and ranged from 2 to 10 individuals per group.

Analysis of the data revealed the following:
GPs and pharmacists were the only health professionals whom participants said they would consult for information about their medicines. They also appeared to have fixed ideas as to the type of information they would seek. For example, the GP tended to be consulted for information that was more clinical in content and usually only if the information could not be accessed elsewhere. The pharmacist was seen as being more accessible and knowledgeable about the actual medicine, including the physical aspects associated with the logistics of tablet taking and clinical issues such as side effects.

“I ask ...about side effects and all the rest of it” (Female, 72, Patient)
“... everything that’s, what your taking, addictive and stuff, anything like that you know”
(Female, 76, Patient)
“.. if I’m...dubious about the side effects... I’ll phone up... the chemist always inform me, if there’s any doubts I can either phone the chemist or phone the doctor...” (Male, 57, Carer)

“I would go to the pharmacist if there was anything about the medication that I didn’t understand”. (Female, 63, Carer)

When asked directly, how they would like to receive information, the majority of participants expressed preference for face-to-face interactions:

“Somebody to tell you personally in the profession, like a doctor or someone”. (Female, 71, Patient)

However, the limited feasibility of face-to-face interactions was accepted and leaflets were mentioned as an accompaniment or alternative source. Participants did consult industry patient information leaflets (PILs) which are dispensed with the medicine but preferred the spoken word:

“Well I always read the labels...When he gets the medication. If there any side-effects or anything... And they all have... If I’m worried about it... I ask”. (Female, 70, Carer)

Only a few of the participants had used the internet for accessing information. It was largely used to investigate side effects or interactions, particularly for new medicines. There were however some comments that the information online can be too detailed or use medical terminology and that it can be difficult to decipher what is relevant and what is not:

“On a website there’s manufacturers, whoever... the ones that make the different medicines... and things like that... but that’s basically it... just to make sure there’s nothing combating or conflicting with the medicines my daughter is on, sort of thing, that it’s ok to take them”. (Female, 58, Carer)

“I go on the internet quite often if it’s a new tablet. I usually put it into a main search... it all comes up, you know, just go into the different ones... Sometimes I think it’s maybe off-putting... you know, you read like say... the after effects and things like that... and it’s a bit... you know maybe you shouldn’t do it, it’s maybe going in too deep”. (Female, 63, Carer)
Requests for information tended to occur when a new or different medicine was prescribed or if any change had occurred to the regular prescription. Participants seemed aware of the practice of generic substitution of medicines and understood the rationale for it, but still wanted to receive reassurance from the pharmacist at the time it occurred, particularly if it resulted in the medicine being a different size, shape, or colour:

“…..my pharmacist, he tells you...he say don’t panic it’s just a different colour or something...he’s good like that” (Female, 67, Patient)

Participants were keen to stress that any consultation with a health care professional was dependent on the type of relationship they had with that individual. It was their familiarity with the health professional that influenced whether or not they would feel comfortable in asking for further information. In that regard, community pharmacists working in small or independent pharmacies were seen as a more approachable resource than those working in busy pharmacies or those run primarily by locums who would have less knowledge of their needs. The participants did appear to appreciate the need for their pharmacist to know specific details about their condition or treatment if it would help the delivery of care. Participants were aware that the pharmacist may not necessarily know about their diagnosis or illness and often they only had the prescription or medicine to base their knowledge upon:

“...if the pharmacist doesn’t know what your condition is they could dispense something which was a genuine mistake, these things happen, whereas if they are clued in on your particular case”. (Female, 66, Patient)

“A lot of chemists now seem to have locums... I find that very off putting”. Researcher: “Is that because they’re not familiar with you? Aye, they don’t know what your background is” (Female, 66, Patient)

“...it’s in the village, it’s a small shop, so...you get to know them. Researcher: Do you think that helps? Oh aye definitely, they remember things about you”. (Female, 63, Carer)
Participants commented on the occasional poor exchange of information and communications between different healthcare settings:

“...and the fact I’ve got to keep the hospital right... I find is the most difficult place...for dealing with medicines...my wife went in with an allergic reaction to the insulin she was on...and that night, they gave her the very same insulin she was allergic to.” (Male, 57, Carer)

This carer surmised that the information in his wife's medical records had not been transferred from her local (primary care) setting to the hospital. Additionally, some participants also felt that communication levels between the pharmacy and the patient could be improved upon in terms of understanding the issues associated with accessing the medicines of someone with a palliative condition:

P1 “...it would be a good idea, to take people like ourselves, every now and again...a half an hour consultation with you [the pharmacist]...it can take an awful weight off your shoulders...You might be happier with everything... then you’d be feeling, confident about going there...and the difficulties become less within yourself... sometimes the circumstances don’t actually change... but see because you get treated if...you know, as if...  

P2: ...you’re somebody?...  

P1: ...aye, then, then you can take the stress off you...  

P3: ...you’re no just a carer!” (P1-P3: 2 Females and 1 Male, 57 – 59 years, Carers)

An interesting point that emerged was that not all participants actually saw their pharmacist. Unlike the GP consultation that generally occurs face-to-face, many participants did not have regular contact with a pharmacist, particularly if their prescription was delivered or collected by someone else. This may limit the usefulness of the pharmacist as an information resource. There appeared to be limited pro-active dissemination of information from the pharmacies, particularly on matters associated with the type and nature of services that they provide. These range from large government funded initiatives such as the Minor Ailment Scheme to bespoke non-funded services such as the collection of prescriptions from GP practices and delivery to patients’ homes. Delivery of medicines should only be offered where appropriate and
should not replace the face-to-face interaction between the pharmacist and the patient and/or their carer. Several of the participants had only found out about services provide from the pharmacy by accident, through a friend or family member or when the situation presented itself, usually in a crisis. For example, one participant spoke of how she became ill with an unexpected ailment and had gone to the pharmacy with the intention of buying an over the counter medicine. It was only during the consultation that she was told that she was eligible to receive treatment via the Minor Ailment Service. Another participant, who was a carer, only found about the prescription collection and delivery service when the practicalities of doing it themselves became problematic. Information about the pharmacists’ extended role appeared to be established largely in a re-active manner:

“I was up one day at the surgery an the girl from the chemist says to me ‘oh Mrs XXXX, you shouldn’t be coming up here. She says “get your medicine delivered”. She says “we’ll get it done”. (Female, Age Unknown, Patient)

Another occasion which illustrated the public’s lack of knowledge around procedures and practice was to do with the collection of CDs. A patient reported an experience where a young male family member (who was unknown to the pharmacist) had appeared at the pharmacy requesting the patient’s pain medicine. The pharmacist had called the patient to confirm the individual’s identity.

“I remember sending my grandson for my painkillers, and I got a phone call from the pharmacists to ask me who it was and what age he was and you know…. its my grandson he’s seventeen. The pharmacist asked what he was wearing, I said [Pharmacist’s name] you’ve seen him in with me, he said I can’t take that as proof, that’s he’s related to you, He (The Pharmacist) is very careful”. (Female, 71 years, patient)

Other group participants said they were aware of the differences in ‘security arrangements’ for CDs. The controlled status of CDs also means that other practices such as ‘borrowing’ small doses to tide the patient over until a prescription is available are also not possible to do. The difference in status between different medicines may need to be communicated better.
Overall, the participants appeared to know little about the wider professional role and services offered by their community pharmacist. Participants’ expectations from their pharmacy appeared to be relatively limited with a key focus on dispensing of medicines in a professional and timely manner.

Discussion:

The data revealed that patients and their carers seek information to become more knowledgeable about the medicines, particularly side effects and the potential for interactions. The literature mirrors these findings. Additionally, patients and carers want re-assurance on the practical aspects of their medicines, such as being forewarned when / if the appearance or dose changes. The GP is consulted largely on issues associated with the condition and only sometimes the medicine. This is largely because it is the GP who has initiated the treatment. Pharmacists, however, tend to be consulted for advice concerning the practical aspects of the medicine, such as how and when to take it. Many of the participants were aware of the practice of generic substitution, and the resulting differences in the physical presentation of the medicine. However, they still wished to receive re-assurance from the pharmacist that the medicine was indeed correct. Pharmacists perhaps need to be mindful of this and keep informing their patients as to why their medicines may look or appear different at times.

The data illustrates that details about pharmacy specific services appear not to be as well advertised as they perhaps could be. Many patients and their carers only found out about pharmacy services if and when the situation arose and not necessarily through official channels. It is important that information about relevant services is made more accessible both through the pharmacist proactively disseminating it, and perhaps through other methods and tailored to patients’ needs. It may also be useful for patients and their carers to know the types of questions that they can direct to their Pharmacist at each visit to the pharmacy. This could be questions about services and more practical matters to do with medicines such as supply and CDs. The data also indicated that patients and their carers prefer to receive information from health professionals with whom they have a close or familiar relationship. The need for a closer relationship with the health professional is also found in the literature [18]. Group participants were not
averse to the pharmacist being informed about the patient’s medical condition if it was used to improve or better manage the service they received. Overall, patients and their carers appeared to be satisfied with the service they received from their Pharmacy. However, since the study cohort was self-selected this may have introduced bias towards participants with a more positive or negative experience.

Poor communication between healthcare settings, particularly in relation to medicines, was cited as a problem. This could lead to patients running out of their medicines, and can be particularly complicated for CDs, as illustrated in the results. This suggests that the situation pertaining to CDs with regards to their dispensing may be an area which could benefit from more pro-active dissemination of information.

Some patients and carers consulted the internet for information on their medicines but this was mainly for re-assurance. However, difficulties in accessing the internet and becoming overwhelmed with the information were seen as barriers to its optimum usage. Participants appeared to use any written information as an accompaniment to the verbal information they may have received.

There are several limitations to the data that should be considered. The nature of qualitative research itself poses limits on the sample size. For instance, it was difficult to recruit participants even though extensive efforts were made through a variety of channels. This may be reflective of the demands made on this population by the research community and also their condition. This sample was further compromised by its demographic composition. The entire group participants were aged over 50 years and hence may not have access to the internet or not feel comfortable with its use. Participants may also still consider pharmacy as predominantly a prescription dispensing based service, compared to the recent move in NHS Scotland to a more patient-focused clinically orientated service. This may explain a lack of awareness of some of the wider pharmacy based services available to the public and their reasons for not considering the pharmacist as a source of information for such services.
**Future Directions**

- Encourage community pharmacies to inform patients on changes in their medicines and work to raise patient and carer expectations of pharmacy services
- Develop a written, easily accessible resource to supplement verbal information educating palliative care patients and their carers on accessing their medicines and information from their community pharmacy
- Identify and promote a list of validated and reliable web-based patient information resources.

### 2.1.2 Optimising information provision for community pharmacies

**Background:**

Phase 1 highlighted the benefits for community pharmacists engaged in the CPPCN. These included an agreed core medicines list to facilitate supply, access to training and opportunities to discuss clinical practice, connection to specialist advice and the local multidisciplinary team.

Despite these findings, a number of challenges within and across network and non-network pharmacies were also identified. Several aspects of the medicines supply process were identified as barriers to patients accessing medicines in a timely manner. These included the failure to identify urgent palliative care prescriptions, inadequate quantities available to fill prescriptions at the time of presentation and limited information resources available at hand for patients (and health professionals) regarding medicines (including unlicensed medicines) used in palliative care. These challenges were particularly pertinent out-of-hours, for locum pharmacists and non-network pharmacies. District nurses and patients reported incidents of having to return to the pharmacy later or the next day to obtain the remainder of the prescription. Phase 1 also highlighted the lack of awareness by pharmacy staff of the nearest network community pharmacy and the contact details of specialist palliative care pharmacists within the NHS Board area. In addition, challenges for continuity of care when prescriptions were presented to a different pharmacy to the one a patient normally used were highlighted.

Furthermore it was identified that community pharmacists have a significant role in
ensuring that all legal requirements in the supply of palliative care medicines are met, particularly with CDs and unlicensed medicines. Significant gaps in prescribers’ knowledge were identified in this area. Extensive and avoidable delays supplying these medicines to patients were identified by pharmacists when prescribing errors had been made, involving additional work for the pharmacist and often the district nurses, as well as patients or carers in obtaining a legal prescription.

It was also noted that information resources available within community pharmacies varied. Some community pharmacies had very little if any palliative care information available for staff and patients, whilst some of the resources relating to palliative care were out of date.

To address some of these gaps in service delivery a single standardised comprehensive palliative care information resource for community pharmacies was proposed.

**Aim:**
To develop and distribute a single standardised comprehensive palliative care information resource for community pharmacies in the NHS GG&C area.

**Methods and Results:**
Contents:
Findings of the baseline report were used to inform the content of the palliative care resource for community pharmacies. Six key sections were developed under the following headings:
- Contacts (Introduction)
- Providing palliative care medicines
- Palliative care prescribing points
- Guidelines and ongoing initiatives
- Patient information
- Network pharmacy

Existing resources were identified and included within the relevant sections. The Macmillan Pharmacist Facilitators led the development of new guidance and/or
materials for inclusion in the final resource, and had overview of the final content, supported by the project administrator.

**Design:**
A folder containing paper copies of all the palliative care resources was chosen as the final format. An electronic resource was considered, however feedback from pharmacists in the baseline study highlighted that access to computers was limited, particularly at peak times in the dispensary, and that accessing information on the shelf was likely to be easier. It was also reported that some large chain pharmacies restrict the number of websites that can be accessed within the dispensaries, which may exclude a number of pharmacists accessing electronic resources.

The size of the folder was selected based on existing pharmacy resource folders, to fit on the pharmacy shelf with a clear marking on the spine to indicate that it is a palliative care resource folder.

The colour purple was chosen to assist with the recognition of the folder containing palliative care resources. Other resources developed as part of the Macmillan project were also printed with a purple background as part of a 'branding' exercise, to identify palliative care resources.

**Distribution:**
The resource folders were hand delivered to each of the project CH(C)P pharmacies in person by the Macmillan Pharmacist Facilitators in April 2011. All other community pharmacies across NHS GG&C received the resource folder by mail, also in April 2011.

In addition, the Head of Pharmacy and Prescribing Support Unit (PPSU) in NHS GG&C promoted and endorsed the Palliative Care Resource folder in the July 2011 PPSU Team Brief, stating that "This resource has been prepared by specialist pharmacists to further develop palliative care services within community pharmacies. It represents a good example of collaborative working across different levels and has been particularly well received by community pharmacists and technicians. I am delighted to endorse the content of the folder to you and strongly recommend its use in practice." [22]
The content of the folder is being reviewed on a regular basis, with an update circulated to all NHS GG&C pharmacies in October 2011. The update included new and revised guidance on medicines used in palliative care and updated contact details for palliative care experts and organisations. Several key documents from the folder have now been added to the NHS GG&C intranet at the request of some community pharmacies.

The Palliative Care Resource folder is included in the Resource Toolkit.

**Future Directions:**

- A short questionnaire is planned for community pharmacists attending NHS Education for Scotland (NES) palliative care training events, seeking feedback on use of the folder in their pharmacies
- Consideration should be given to rolling out the folder as a national resource across other NHS Boards in Scotland. A questionnaire has been circulated to each NHS board, mainly via the Scottish Palliative Care Pharmacists Association, seeking feedback on the relevance of the contents to other Board areas
- Consideration should be given to moving this resource to an electronic platform to ensure longer term sustainability
- Continue to work with chain pharmacy IT support to ensure access to educational electronic resources. (During the project period lists of key palliative care websites were forwarded to the relevant head offices of the largest pharmacy multiples and these sites are now accessible within their respective pharmacies).

**2.1.3 Information resources for multidisciplinary health care teams**

*Background:*

Medicines are one of the most commonly used health care interventions, and are key in the management of symptoms in palliative care. In the community setting the supply of medicines to patients is a multi-step process (prescription, dispensing and delivery), and often involves CDs, medicines being used ‘off-label’ and ‘unlicensed’ medicines. In
some cases advice may be sought from a specialist in palliative care.

Phase 1 identified a number of gaps in the supply of medicines to palliative care patients in the community. These included:

- limited awareness, by prescribers, care home staff, and non-network pharmacists, of the specific palliative care medicines held in Network Pharmacies
- limited knowledge of the legal requirements when prescribing CDs
- lack of awareness of the indications, prescribing information (e.g. dose, pack size) and availability of unlicensed medicines used in palliative care.

Issues had also been identified from prescribing and pharmacy data sources regarding the appropriate prescribing of specific palliative care medicines (e.g. midazolam and levomepromazine).

The above issues highlighted the need for concise and accessible information regarding medicines commonly used in palliative care and guidance on how to comply with the legal requirements for prescribing Controlled Drugs.

**Aim:**

To develop information resources to assist practitioners with the appropriate selection, legal requirements for prescribing, and the supply of palliative care medicines.

**Methods and Results:**

A range of prescribing prompts and resources were developed based on the findings of Phase 1 and other data sources as described above. These included a *Palliative Care Prescribing Aid*, providing guidance on writing prescriptions for CDs and unlicensed or off-label medicines, and a reminder of existing palliative care resources. Prompts were also developed tailored to address specific issues in the prescription of palliative care medicines. Two specific examples, developed to address the frequently reported midazolam and levomepromazine prescribing errors, are included in this chapter. Guidance on unlicensed medicines has also been developed, in co-ordination with the
NHS GG&C Specialist Palliative Care Pharmacists.

Palliative Care Prescribing Aid

Development:
The content of the Palliative Care Prescribing Aid was developed by the Macmillan Pharmacist Facilitators, in consultation with two General Practitioners within the project CH(C)Ps. The final draft was reviewed and approved by the Local Medical Committee (LMC) (representing all NHS GG&C GP’s) and the Primary Care Prescribing Management Group (PCPMG). The timeline for development is outlined in Table 5.

Design:
- The final size of the Palliative Care Prescribing Aid was designed to complement existing resources available in primary care, being a similar size to the BNF and existing guidelines that are available in A5 booklet format.
- The colour purple was chosen for the background, to align with existing palliative care resources.
- A hole punch was inserted at the top of the prompt to assist with displaying on notice boards and/or as a bookmark.

Communication Strategy/Distribution:
The Palliative Care Prescribing Aid was distributed to:
- All GP practices via a local NHS mailing system and to all district nurses within NHS GG&C
- The Care Homes Medical Practice and Care Homes Nurse liaison team which support care homes in the Glasgow area of NHS GG&C
- All locum and after hours GPs in NHS GG&C via the ‘GP Performers List’
- The out-of-hours hub at Caledonia House (to be placed in all on-call bags)
- All community pharmacies as part of the Palliative Care Resource Folder update in October 2011 (see Section 2.1.2)

A pre-printed letter was sent to all GPs along with the Palliative Care Prescribing Aid in an NHS branded envelope. The NHS branding was used to distinguish the Palliative Care Prescribing Aid as an NHS resource and reduce the risk of recipients perceiving the prompt was from other sources. To raise awareness of circulation of the resource to
GPs, lead CH(C)P pharmacists across NHS GG&C wrote to all practice managers within their relevant CH(C)Ps informing them of the planned correspondence to the GPs.

The distribution of the *Palliative Care Prescribing Aid* and accompanying letter has resulted in requests from over 35 practices/locum GPs for additional copies of palliative care resources (NHS GG&C palliative care guidelines booklet and community pharmacy palliative care network leaflet).

**Table 5: Timeline for development of the *Palliative Care Prescribing Aid*.**

<table>
<thead>
<tr>
<th>Month</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Month 1</td>
<td>Content developed</td>
</tr>
<tr>
<td>Month 2</td>
<td>Content approved by LMC and PCPMG (NHS GG&amp;C)</td>
</tr>
<tr>
<td>Month 3</td>
<td>Graphic design</td>
</tr>
<tr>
<td>Month 4</td>
<td>Printing</td>
</tr>
<tr>
<td>Month 5</td>
<td>Distributed to GP practices, and district nurses</td>
</tr>
<tr>
<td>Month 6</td>
<td>Distributed to non-practice based GPs</td>
</tr>
<tr>
<td>Month 7</td>
<td>Distributed to community pharmacies</td>
</tr>
</tbody>
</table>

The final version of the Palliative care prescribing aid is included in the resource toolkit. The palliative care prescribing aid was presented at a national palliative care conference in October 2011.

*Midazolam*

Injectable midazolam used in palliative care is preferably prescribed as a specific ampoule strength, as the more dilute strengths may result in too large a bolus being required to be administered subcutaneously and/or too large a volume of fluid to fit in a syringe pump. Prescribing data analysed from the Prescribing Information System for Scotland (PRISMS) for June 2009-May 2010 demonstrated that across NHS GG&C approximately 50% of all midazolam prescriptions were written for the wrong strength or ampoule size. A specific incident involving an incorrect prescription was identified in which a carer visited five different pharmacies before the error was rectified with the prescriber.
To improve midazolam prescribing a range of prompts for healthcare professionals were developed. Issues regarding the prescribing of midazolam ampoules were highlighted to GPs in NHS GG&C via the PostScript Primary Care Bulletin in August 2010. A copy of the Bulletin is included in the Resource Toolkit [15].

In addition, guidance on the use of midazolam in palliative care has been included in the Palliative Care Resource Folder, distributed to all community pharmacies in NHS GG&C. A sample of a correctly written midazolam prescription was also included, to be shared with GPs when incorrect prescriptions have been presented to the community pharmacist. Issues regarding the use of midazolam in palliative care were also discussed with district nurses, to assist with ensuring appropriate prescribing by the GPs, prior to the prescription being presented to the community pharmacy.

**Levomepromazine**

In low doses, levomepromazine is used for the management of intractable nausea/vomiting. A number of medication incidents involving levomepromazine had been reported to members of the palliative care team. There are two strengths of levomepromazine tablets available, a 25mg licensed preparation and a 6mg unlicensed preparation. Errors arose due to the lower strength tablet not being listed on GP prescribing systems, nor in the regular section of BNF (it is listed in the palliative care section of the BNF). The 25mg tablet was being prescribed with the expectation that patients or carers would quarter the tablet. This practice led to inaccurate dosing due to the tablet crumbling when cut. There were also incidents reported in which the 25mg tablet was prescribed in error, without any instructions to quarter the tablet, leading to patients experiencing adverse side effects, and, in at least one case, hospital admission.

A levomepromazine PIL, that included information for both patients and health care professionals, was developed by one of the Macmillan Pharmacist Facilitators to raise awareness of the 6mg tablet and reduce the number of levomepromazine related medication incidents. The content of the PIL was approved by the NHS GG&C quality co-ordinator prior to printing and distribution.
In contrast to other prompts developed as part of the Macmillan project, the levomepromazine PIL prompt was designed to be patient led. The intention was that patients initiated on levomepromazine were issued with the PIL and requested to present it to members of the healthcare team at each appointment/visit, to prompt correct prescribing and procurement of the 6mg tablet formulation. In addition to the PIL, guidance on the procurement of levomepromazine was distributed to community pharmacies via the Palliative Care Resource folder (see Section 2.1.2).

**Guidance on unlicensed medicines**

Unlicensed medicines and medicines being used off-label do not have UK approved prescribing and therapeutic information available. During the Macmillan project a number of guidance documents were developed by the specialist palliative care pharmacists, to provide information to healthcare professionals on unlicensed or off-label medicines used in palliative care. A specific example is the guidance developed for “antacid and oxetacaine oral suspension”, an alternative for the discontinued Mucaine® suspension.

Guidance included information on indication for use, pharmacology, dose, composition, precautions/contraindications, drug interactions and procurement processes. This guidance was circulated to all NHS GG&C pharmacies as part of the update of the Palliative Care Resource folder (see Section 2.1.2) in October 2011.

**National Dissemination**

The ongoing support of the SPCPA has helped to ensure a national perspective for the project work. The resource folder has been distributed to SPCPA members in each Health Board in Scotland. A questionnaire to scope the potential application of the folder across Scotland has been developed, and responses to this are awaited. Likewise, the Scottish Partnership for Palliative Care have been supportive of the project work, and have been regularly updated on progress.
Future directions:

- The resources developed should be shared with palliative care specialists, including Clinical Nurse Specialists.
- Consideration should be given to the sharing of these resources as tools to promote best practice, through existing national networks.
- Consideration should be given to sharing these tools with health professionals working in supported care settings, such as care homes.
- Guidance for unlicensed and off-label medicines used in palliative care medicines should continue to be developed, as part of patient care.

2.2 Communication/Networking

Background:
Phase 1 identified numerous challenges regarding communication and engagement in delivering palliative care services, including varied communication between GPs and community pharmacists, and varied engagement and support between network and non-network pharmacies. A lack of awareness by care home staff of the community pharmacy palliative care network was also identified, with incidents and complaints about access common. A number of suggested interventions were identified to improve overall communication and professional engagement, such as improving CPPCN awareness, and multidisciplinary training/clinical review sessions to support networking and sharing of good practice.

Aim:
To describe communication strategies and networks used and/or developed by the Facilitators across the four project CH(C)Ps relevant to palliative care services. To reflect upon the perceived strengths, weaknesses and sustainability of each of the strategies identified to inform an evidence-based model of community pharmacy services in palliative care.

Methods:
The four Macmillan Pharmacist Facilitators were asked to complete the Communications Development Exercise form to describe current communication
strategies and networks they utilised in their CH(C)P. The form is included in the Resource Toolkit. The exercise was completed between March and April 2011, and consisted of a retrospective analysis of their practice in the previous 12 months.

The Facilitators were also asked to consider and report on the perceived strengths, challenges and sustainability for each of the communication strategies and networks, and to record suggestions as to how to improve current strategies. These were shared at a specially convened Facilitators meeting. Responses were collated and analysed by a member of the university team. Preliminary results were presented to the Facilitators and the Project Lead for discussion and clarification of any questions raised by the analysis. Reflections from the Project Lead regarding the progress achieved by December 2011 against the project action plan were also sought, which identified further strategies. The final results incorporate the feedback from the group discussions and reflections by the Project Lead.

Results:
A broad range of communication strategies with their perceived strengths and weaknesses were identified by the Pharmacist Facilitators, as detailed in Table 6. Strategies included a mix of both one-to-one interactions between the Facilitator and various members of the community palliative care team as well as involvement of the Facilitator in established group meetings and education sessions. Figure 1 presents these strategies visually in the context of pharmacy-based activities and multidisciplinary activities.

The findings illustrate the interactive role that the Facilitators play, for example, in the distribution of the baseline (Phase 1) questionnaires, and delivery of the Palliative Care Resource Folders. These and other activities (Figure 1) targeted both pharmacy staff and members of the multidisciplinary team. The face-to-face contact given by the Facilitators was intentional and integral to their role, and would have occurred regardless of which aspect of the project action plan was being completed at that time.

The issue of sustainability was discussed with the Facilitators in relation to each communication strategy presented. It was recognised that in many cases this was
identified as person specific i.e. dependent upon the Facilitator to initiate and/or deliver. Facilitators were asked to reflect on how the evolving strategies could be made more system dependent and thus more resilient through the evolving development of the community pharmacy palliative care network moving forward.
### Table 6: Communication strategies identified by the Pharmacy Facilitators and Project Lead

<table>
<thead>
<tr>
<th>Communication strategy</th>
<th>Strengths</th>
<th>Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Pharmacy-based activities</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Community Pharmacy visits (scheduled and ad-hoc visits)    | • Both network and non-network pharmacies are visited, thus improving awareness of the CPPCN and of current initiatives  
• Allow individual questions to be raised and issues addressed on a one-to-one basis.  
• Good for relationship building between the Facilitator and the pharmacist and pharmacy staff  
• Ability to target pharmacies supplying large number of care homes  
• Staff numbers in some pharmacies make delivery of staff training within the pharmacy worthwhile; opportunities to liaise with senior managers for the care home service | • Time consuming for the Pharmacist Facilitator (20-30 minutes per visit)  
• Community pharmacists may not always have time to discuss issues fully, if at all  
• Equity across all pharmacies supplying care homes |
| Training days (Induction and updates for network pharmacists, support staff, NES) | • Sessions are generally well attended (noting that attendance at the annual updates are compulsory)  
• Encourage information sharing between pharmacies within a locality, and cascade of learning to other staff in their pharmacy  
• Participation counts towards CPD (incentive)  
• Accessible, as events are held in various areas and locum costs can be claimed as well as a fee for support staff attendance to allow backfill  
• Provide opportunities to raise issues and share important messages with a larger group | • Some pharmacies are less engaged than other pharmacies  
• Difficult to arrange the timing of events (e.g. daytime or evening), to suit all participants  
• Time consuming to organise, which may impact on the schedules of the Facilitators, but has released time for area specialist pharmacists  
• Geographical issues – difficult to attract staff who have furthest to travel |
| Pharmacy prescribing support staff meetings                 | • Opportunity to share information for feedback to GP surgeries and members of the CPPCN  
• Increased awareness of the CPPCN and reinforces the message that palliative care is everyone's business  
• Prescribing support team already influences GP prescribing | • Attendance is varied, based on the availability of participants |
| Pharmacy locality meetings (bi-monthly)                    | • Opportunity to liaise with a large number of pharmacists at the one time  
• Promotes interaction with pharmacists that were not visited one-to one  
• Opportunity for network and non-network pharmacists to meet and establish working links  
• Potential for involvement in education through practice development (e.g. local just-in-case training, LCP etc), and for peer review  
• Ensures palliative care is high on the agenda | • Attendance can be low, which may be due to the fact that meetings were often held in the evenings  
• Pharmacists with strong views may unduly influence others  
• Issues in gaining the confidence and trust of others  
• Not all CH(C)Ps have locality meetings  
• Most pharmacists live outside their work areas |


<table>
<thead>
<tr>
<th>Multidisciplinary activities</th>
<th>Links with prescribing team within the CH(C)P</th>
<th>One-to-one visits with Practice Managers</th>
<th>Contact with lead / district nurses (ad hoc by telephone and face to face meetings)</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Refreshments such as hot food are available, which can improve attendance and may find it difficult to attend</td>
<td>• Facilitates individual clinical enquiries about patients • Increases the individual palliative care knowledge base of prescribing support pharmacists • Allows promotion of palliative care initiatives, as well as awareness of, and support for, the CPPCN</td>
<td>• Increases the awareness and functions of the CPPCN, as well as how to access the service.</td>
<td>• District nurses enthusiastic to improve links with pharmacists • Opportunity to discuss and resolve any local issues (e.g. identifies system failures through actual incidents) • Opportunities for shared learning and improvements</td>
</tr>
<tr>
<td>• Visits are dependent on the availability of the Practice Manager (not always available)</td>
<td></td>
<td></td>
<td>• Difficulties in identifying joint training or meeting opportunities due to busy schedules • Recent merge of CH(C)Ps resulted in the appointment of new lead nurse, requiring the re-establishment of links and networking relationship • Changing established practice (e.g. 'direction' of prescriptions to a specific pharmacy stocking palliative care medicines which may not be the patient's regular pharmacy)</td>
</tr>
</tbody>
</table>

| CH(C)P Locality Palliative Care Group/Forum                                                                 | Attended by representatives from multiple professions and agencies involved in providing palliative care • Facilitates interaction across agencies and professions • Allows promotion of the CPPCN and the input of clinical pharmacy services into palliative care | | • Some CH(C)P groups more established than others • The recent merging of CH(C)Ps resulted in no meetings for over a year in some areas • Variable attendance |
| Multidisciplinary Team Bulletins and Board-wide Committees                                                                 | Raise awareness of the CPCCN, the Macmillan project and palliative care issues (e.g. midazolam prescribing) • Reaches a wide audience • Not time intensive | | Unsere if individuals read the bulletins Fixed scheduling of these meetings restricts facilitators ability to attend due to their working pattern |
| Attendance at care homes training sessions (e.g LCP)                                                                 | Increased awareness of the CPCCN, the medicines stocked and how to access them | | Raising awareness with care home staff of importance of adequate communication with their community pharmacy (e.g. urgency of prescription) |
Figure 1: Categorisation of communication strategies - Pharmacy or multi-disciplinary activities

Pharmacy based activities

- Pharmacy Prescribing
- Support Staff Meetings
- Community Pharmacy Visits
- Training Days

Multi-disciplinary activities

- Prescriber Team Links
- Lead / District Nurse Links
- Practice Manager Visits
- CH(C)P Locality Palliative Care Group / Forum

Circulating Baseline Questionnaires
Distributing Resource Folders
**Future Directions:**

- Macmillan Pharmacist Facilitators should continue to play a lead role in establishing and strengthening communication strategies across the CH(C)Ps.
- Existing networks should continue to be used to facilitate communication of relevant palliative care issues (e.g., using the links with the prescribing support team to feedback palliative care prescribing issues to the GPs).
- Further work is required to identify the information, communication and support needs for care home staff to improve pharmaceutical palliative care for their residents.
- Consideration should be given to how communication strategies can become more system dependent than person dependent.
- Consideration should be given to existing networks for Facilitators to reach non-network pharmacy staff e.g., through NES.
- Consideration should be given to the ongoing leadership, coordination and support from the Project Lead and Project Administrator to ensure communication between the project team and external agencies.

**2.3 Skills Development**

**2.2.1 Pharmacy support staff**

*Background:

In Phase 1 it was recognised that community pharmacy support staff sometimes fail to differentiate palliative care prescriptions or did not appreciate the urgency often associated with them. It was also recognised that within the community pharmacy setting, support staff are probably reasonably static in terms of their place of work, and are less likely than pharmacists to move between pharmacies. Hence support staff represent a potential continuous presence in the delivery of palliative care pharmacy services. This is in contrast to pharmacists’ working patterns, in which after-hours pharmacists or locum pharmacists are employed on a regular basis, who may not be aware of, or know how to access, the CPPCN or relevant palliative care resources available to them. This lack of awareness may lead to gaps in continuity of care for palliative care patients. Up-skilling of the support staff would encourage a broader 'pharmacy' awareness and approach to palliative care services, in addition to the expertise provided by the pharmacist as an individual.
No existing education or training programmes in palliative care were in place for pharmacy support staff within the four CH(C)Ps, nor across NHS GG&C.

_Aim:_
To develop and implement an education and training programme open to network pharmacies in the four project CH(C)Ps, to address the gaps in service delivery identified in Phase 1 relevant to pharmacy support staff.

_Methods:_
Findings from Phase 1 pertaining to this topic were analysed to identify objectives and topics for the education and training sessions.

Education sessions were promoted through the distribution of flyers to the network pharmacies via existing communication mechanisms. Each Facilitator then followed up this distribution with phone calls to pharmacies to increase awareness and potential attendance.

All participants were issued with a certificate of attendance. Network pharmacies were reimbursed £50 for each staff member in attendance. This could be used to cover the cost of replacing the staff member. Light refreshments were provided at the events.

After the events, Facilitators conducted follow-up visits with the participants to obtain feedback on the content of the session and to identify lessons learned or practice changes as a consequence of what they learned.

_Results:_
A total of six education sessions were held during the reporting period (until December 2011). For reporting purposes the education sessions are split into two groups; Series 1: three education sessions conducted between June 2010 and February 2011; Series 2: three education sessions conducted in September 2011. Each session was conducted over a two and half hour period.
Series 1

The first three education sessions were held at a central location in the city of Glasgow, between June 2010 – February 2011. The city of Glasgow was identified as being accessible by network pharmacy support staff across the 4 project CH(C)Ps. Based on the findings of Phase 1, the education sessions addressed the following topics:

- Introduction to palliative care
- Recognising, checking and prioritizing palliative care prescriptions
- Raising awareness of palliative care resources with your colleagues in your community pharmacy
- Identifying patient resources for palliative care
- Syringe pumps.

A similar content and format was used in each of the three sessions which included oral presentations and workshops. Two separate workshops were run concurrently, targeting counter staff and technicians/dispensary staff, respectively.

The education sessions were delivered by specialist palliative care pharmacy technicians working in local hospices and one facilitator, and were supported by the NES National Co-ordinator for Pharmacy Support Staff Educational Development, the Macmillan project administrator and project lead.

A total of 22, 19 and 18 pharmacy support staff attended the three education sessions, respectively. Further details of the participants at each session are described in Table 7.

Participants represented network pharmacy support staff from three of the four project CH(C)Ps. There were no participants from the Inverclyde CH(C)P.

Feedback obtained through the follow-up sessions conducted by the Facilitators indicated that the education sessions were of value to those who attended:

‘..it was one of the most useful training days (I have) attended’
‘..(I)see the absolute benefit of knowledge acquired for days when the regular pharmacist wasn’t there (in the pharmacy)’

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The sessions raised the overall awareness of the needs of palliative care patients, medicines commonly used in palliative care, and the value of routine stock checks of the range of medicines network pharmacies agreed to stock.

One Facilitator noted, in asking participants to reflect on what they had learned, a greater appreciation and sensitivity towards palliative care patients:

‘a palliative care patient may not be imminently dying’, ‘Be more sensitive when dealing with palliative care customers…’, ‘Reduce waiting times for people with palliative care prescriptions’

‘Being able to recognise when the patient or representative may need more support.’

There was also a raised awareness of the role of other health professionals in the management of palliative care patients as well as the role of the community pharmacy:

‘…look out for nurses as they come in and also letting them know we do palliative care.’
‘.. contact our surgeries to inform them that we are now a palliative care pharmacy’.

With respect to managing palliative care medicines within the pharmacy, nearly all participants reported a commitment to implement systems to ensure stock availability:

‘Have a date and stock check rota to ensure is done every week’, ‘Pay particular attention to stock list of palliative care drugs held in pharmacy and check shelf stock’
‘Check stock regularly and order when required’.

In addition participants reported a greater awareness of the palliative care courier service, and the need to ensure that the rest of the pharmacy team was aware of services and resources available. Staff also reported the training sessions had made them more confident when dealing with difficult situations such as delivering medicines to the home of a terminally ill patient and had enabled them to signpost carers to relevant support services.
Areas identified by the support staff for future education sessions include further information on syringe pumps, when to use the courier service, and the contents of the ‘Palliative Care Resources’ folder for community pharmacies which was at the development stage at the time of the first series of education sessions.

Series 2
The second series of three education sessions were held in September 2011. In contrast to Series 1, these were held in different local venues across the project CH(C)Ps, in South West Glasgow, Greenock and West Dunbartonshire, respectively. The localisation of education session venues aimed to increase overall attendance. To engage with a broader range of support staff the second series of education sessions were advertised to support staff from both network and non-network pharmacies across the 4 project CH(C)Ps.

Topics addressed in the second series of education sessions were based on the feedback from the previous sessions and included:

- Role of CPPCN
- Resource Folder
- Courier Service
- Difficult conversations
- Communication skills
- Syringe pumps

A similar content and format was used in each of the three sessions.

The total number of participants in each of the second series of education sessions are outlined in Table 7.
Table 7: Participants at the pharmacy support staff education sessions

<table>
<thead>
<tr>
<th>Session</th>
<th>Time of day</th>
<th>Technicians</th>
<th>Dispensers</th>
<th>Counter staff</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Series 1 (June 2010 – February 2011)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Morning</td>
<td>10</td>
<td>5</td>
<td>7</td>
<td>22</td>
</tr>
<tr>
<td>2</td>
<td>Afternoon</td>
<td>6</td>
<td>8</td>
<td>5</td>
<td>19</td>
</tr>
<tr>
<td>3</td>
<td>Evening</td>
<td>8</td>
<td>8</td>
<td>2</td>
<td>18</td>
</tr>
<tr>
<td><strong>Series 2 (September 2011)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Evening</td>
<td>3</td>
<td>6</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td>2</td>
<td>Evening</td>
<td>13</td>
<td>4</td>
<td>2</td>
<td>19</td>
</tr>
<tr>
<td>3</td>
<td>Afternoon</td>
<td>4</td>
<td>1</td>
<td>-</td>
<td>6*</td>
</tr>
</tbody>
</table>

*plus 1 pre-registration pharmacist

Feedback from the participants of the second series of education sessions was sought, and confirmed that these sessions were highly valued by the participants:

“Didn’t have very much knowledge at all so found all sessions very informative”, “I enjoyed all the topics”, “All sessions were very useful as you could see different processes and what is available out there for patients and their families or carers” and “All of it, I am better informed”

When asked which session participants found useful, feedback included the following:

“The end session….. especially the chance to be able to see the syringe driver”, “Difficult conversations – relate to all he was saying, help with future conversations” and “Dealing with (the) patient and finding out about the purple folder”.

When asked about the suitability of the venue a number of participants highlighted the ease of access across the three local venues:
“Great! – local and not Glasgow”, “Excellent, very central” and “Very suitable/easy to access”

The second series of education sessions were coordinated in conjunction with NES, and featured a multi-disciplinary approach with input from local district nursing staff, Macmillan pharmacist facilitators, palliative care technicians and presentations/workshops from education facilitators from local hospices. Despite efforts to publicise the events it remained a challenge to get good numbers to attend.

Future Directions:

- Feedback from the education sessions will be used to inform future education sessions for pharmacy support staff across the NHS GG&C area. Two further sessions, open to staff in network and non-network pharmacies, have been planned for February/March 2012.
- Experienced network pharmacists will be asked to assist with facilitating training sessions, to prepare them to take on aspects of the trainer role in the future.
- Consideration should be given to the development of e-learning tools for pharmacy support staff education modules; an initiative in conjunction with NES is already underway to develop an initial resource on palliative care for pharmacy technicians.
- A series of articles on palliative care has been proposed, to appear in pharmacy magazines that are widely available within community pharmacies.
- Education opportunities for pharmacy technicians should be developed to support the registration requirements with the General Pharmaceutical Council, which includes a commitment to continuing professional development.
2.2.2 **Network Pharmacists**

Prior to the commencement of the Macmillan project, a training and education programme for network pharmacists had been implemented across NHS GG&C, but was not always well planned throughout the year and induction training for pharmacists new to the network was not always timeously available to all pharmacists. This education programme was enhanced and further developed throughout the duration of the reporting period, and included quarterly induction training sessions and update education sessions on several occasions each year.

The Macmillan Pharmacist Facilitators assisted in the coordination and delivery of the education programme. This has resulted in freeing up some of the specialist pharmacists’ time, and the ability to deliver more education sessions.

In addition, the involvement of the Facilitators in the education programme has increased opportunities for interactions between community pharmacists and the Facilitators, resulting in a raised awareness of the Facilitator role. The Facilitators were also able to introduce pharmacists to other pharmacists working in their local area, strengthening communication channels and promoting networking at a local level.

**Future Directions:**

- Facilitators should continue to coordinate the educational programme, to ensure the sustainability of core skills training for network pharmacists.
- Consideration should be given to the potential for experienced community pharmacists in the network to deliver some of the training.
- Educational needs of network pharmacists should be assessed by the Facilitators on a regular basis to inform future training sessions.
- In the current year, pharmacists are being encouraged to assess their own development needs and spend a day with other members of their local teams delivering palliative care services.
2.2.3 Clinical skills in symptom management

Background:
Phase 1 identified a lack of continuity of service provision in the CPPCN, particularly out of hours, and across the clinical team in both primary and secondary care. A need to continue to develop the education and training resources available to support community pharmacists both within and out with the network was identified.

In response to these challenges a study was designed to test the feasibility of a pharmaceutical care plan (PCP) document for palliative care patients. This resource could potentially become embedded within the evolving Chronic Medication Service (CMS) currently available in all community pharmacies across Scotland. The rollout of CMS includes a generic electronic infrastructure to support pharmaceutical care. This study was developed in part fulfilment of the requirements of the project component for the MSc in Clinical Pharmacy at the University of Strathclyde.

Aim:
- To develop a PCP to support community pharmacists delivering the CMS to palliative care patients.
- To identify the level of confidence of community pharmacists in identifying and discussing common palliative care patient needs, and seek community pharmacists’ views on incorporating palliative care into CMS.

Methods:
Development of pharmaceutical care plan to underpin the CMS – a detailed comparison between a care plan [23] generated from evidence based guidelines, and care issues collated from a field study of palliative care patients’ case notes compiled by one of the Facilitators, generated an initial list of palliative care issues. This was augmented with evidence from the NES training package for palliative care [24], the GSF prognostic indicators guidance [25], CMS electronic template [26] and the NHS GG&C guidelines for palliative care [27] to produce a final set of pharmaceutical palliative care issues. The current electronic CMS documentation system in the community pharmacy setting was examined and used as the template for designing a pharmaceutical care plan for palliative care patients.
Community pharmacist questionnaire - A self-completion questionnaire (detailed and summarised in Tables 8 and 9) was designed to explore community pharmacists’ confidence in identifying and discussing common palliative care issues, with a focus on pain management, and their views on integration into the CMS. The questionnaire was field tested, modified and underwent face validity testing by a specialist palliative care pharmacist. Community pharmacists (both network and non-network) identified by two of the Facilitators from the project CH(C)Ps were invited to complete the questionnaire during July 2011.

Results:
Pharmaceutical care plan for palliative care patients - The overarching framework for the content of the PCP was based on the electronic CMS Pharmaceutical Care Record. This comprised of generic sections to document medical history and medicines, standard treatment verification and individual care issues. It was augmented by the derived care plan for palliative care patients illustrated in Table 8 and designed into three main sections: ‘patient specific’ information, ‘disease specific’ monitoring data and ‘standard checks’ to allow identification of palliative care issues.

Community Pharmacist Questionnaire Findings - Twenty community pharmacists completed the questionnaire. The majority were female (n=13, 65%), with a median period since qualification of 6 years (range 1-29), and worked in a community pharmacy a median of 5 days per week (range 1-6). Nine pharmacists (45%) were members of the CPPCN.

Table 9 summarises participants’ level of confidence in identifying and discussing common clinical problems faced by palliative care patients, and which they, or their carers, may present to a community pharmacist. There is a general decreasing trend in the level of confidence as the clinical problems they are presented with move from management of pain, to disease or treatment complications/adverse drug reactions, and to more specialised problems which may necessitate accessing clinical records. This information provides an early indication of potential areas for inclusion in training resources to support community pharmacists so that they may provide a consistent
high level of pharmaceutical care.

Eleven (55%) participants reported completing a Continuing Professional Development (CPD) record on pharmaceutical care for palliative care patients; however most of the sample (95%) indicated they were planning to do so. When participants were asked about incorporating palliative care patients within the CMS, 14 participants (70%) agreed, providing reasons that centred on better identification of issues and improved patient care. Seventeen (85%) pharmacists supported the inclusion of an electronic PCP specifically for palliative care patients within the CMS electronic documentation system.

As part of the Custodian review, by members of the Scottish Palliative Care Pharmacists Association including one of the Macmillan facilitators, of the NES web-based resource ‘Pharmaceutical Care of people requiring palliative care’, an assessment tool was developed aligned with the electronic format of the Pharmaceutical Care Record for the CMS. Results from the Macmillan project investigating the feasibility of the approach of a PCP, directed the content of the assessment tool, in combination with the content of the previous version of the NES resource. The assessment tool developed has a focus on clinical skills where the level of confidence of community pharmacists was the highest, and a simpler format than the PCP tested as part of this project, and is to be piloted as part of future project activity.

Future Directions:
• These findings provide early evidence to indicate that a pharmaceutical care plan, providing a summary of the common pharmaceutical care issues faced by this population would be welcomed by community pharmacists in their support of this vulnerable patient group.

• The designed PCP should be field tested with community pharmacists, together with establishing the information technology steps necessary to support this through the evolving CMS.

• Consideration should be given to extending CMS services to care home patients.

• Future training resources should be tailored to address the identified levels of confidence in identifying and discussing pharmaceutical care issues.

• Future training of pharmacists should include anticipatory care and supplementary/independent prescribing to support the symptom management care provided by pharmacists.
**Table 8: Palliative care plan for patients with palliative care needs**

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Pain</th>
<th>Nausea</th>
<th>Vomiting</th>
<th>Bowel obstruction</th>
<th>Breathlessness</th>
<th>Anorexia</th>
<th>Constipation</th>
<th>Diarrhoea</th>
<th>Anxiety (patient)</th>
<th>Anxiety (carer)</th>
<th>Confusion</th>
<th>Depression</th>
<th>Fatigue</th>
<th>Agitation</th>
<th>Cough</th>
<th>Dysphagia</th>
<th>Dry eyes</th>
<th>Mouth problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date/sign</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Standard Checks</th>
<th>Care Issue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncontrolled pain despite analgesia</td>
<td></td>
</tr>
<tr>
<td>Change in nature and severity of pain</td>
<td></td>
</tr>
<tr>
<td>Adjunctive analgesics prescribed</td>
<td></td>
</tr>
<tr>
<td>Breakthrough pain analgesia prescribed</td>
<td></td>
</tr>
<tr>
<td>Knowledge of medication and aims of treatment</td>
<td></td>
</tr>
<tr>
<td>Patient is unable to take oral dosage forms</td>
<td></td>
</tr>
<tr>
<td>Syringe driver/pump required</td>
<td></td>
</tr>
<tr>
<td>Poor oral intake due to nausea and vomiting</td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td></td>
</tr>
<tr>
<td>Diarrhoea</td>
<td></td>
</tr>
<tr>
<td>Patient is wheezing</td>
<td></td>
</tr>
<tr>
<td>Patient is on oxygen</td>
<td></td>
</tr>
<tr>
<td>Patient is on benzodiazepines</td>
<td></td>
</tr>
<tr>
<td>Patient is on inhaled bronchodilators</td>
<td></td>
</tr>
<tr>
<td>Patient too weak to use inhalers</td>
<td></td>
</tr>
<tr>
<td>Patient uses nebuliser</td>
<td></td>
</tr>
<tr>
<td>Dysphagia</td>
<td></td>
</tr>
<tr>
<td>Patient is on enteral feeding tube</td>
<td></td>
</tr>
<tr>
<td>Mouth problems</td>
<td></td>
</tr>
<tr>
<td>Skin problems</td>
<td></td>
</tr>
<tr>
<td>Fluctuating level of consciousness</td>
<td></td>
</tr>
<tr>
<td>Risk of adverse GI problems</td>
<td></td>
</tr>
<tr>
<td>Contraindications</td>
<td></td>
</tr>
<tr>
<td>Drug interactions</td>
<td></td>
</tr>
<tr>
<td>Pharmacokinetic risk factors</td>
<td></td>
</tr>
<tr>
<td>Pharmacodynamic risk factors</td>
<td></td>
</tr>
<tr>
<td>Specialist palliative care medicine prescribed</td>
<td></td>
</tr>
<tr>
<td>Patient is on unnecessary medicines</td>
<td></td>
</tr>
</tbody>
</table>

**Pharmaceutical Care Plan for Patients With Palliative Care Needs**

<table>
<thead>
<tr>
<th>Name</th>
<th>Address</th>
<th>GP</th>
<th>Social circumstances</th>
<th>Carer Name</th>
<th>Date/Sign</th>
<th>LFTs</th>
<th>eGFR</th>
<th>Electrolytes</th>
<th>Blood count</th>
<th>Glucose</th>
<th>Disease Specific Monitoring Data</th>
<th>Date/sign</th>
<th>Pain</th>
<th>Nausea</th>
<th>Vomiting</th>
<th>Bowel obstruction</th>
<th>Breathlessness</th>
<th>Anorexia</th>
<th>Constipation</th>
<th>Diarrhoea</th>
<th>Anxiety (patient)</th>
<th>Anxiety (carer)</th>
<th>Confusion</th>
<th>Depression</th>
<th>Fatigue</th>
<th>Agitation</th>
<th>Cough</th>
<th>Dysphagia</th>
<th>Dry eyes</th>
<th>Mouth problems</th>
</tr>
</thead>
</table>

**Notes:**
- Use 'Yes' or 'No' for most symptoms.
- Use 'Presenting' for any other relevant medical conditions.
- Use 'Known' for any known allergies or sensitivities.
- Use 'Impaired' or 'Normal' for lab results.
- Use 'High risk medication' if any high-risk medications.
- Use 'Specialist advice' for any specialist advice.
- Use 'Risk of adverse GI problems' for any risk of adverse GI problems.
- Use 'Contraindications' for any contraindications.
- Use 'Drug interactions' for any drug interactions.
- Use 'Pharmacokinetic risk factors' for any pharmacokinetic risk factors.
- Use 'Pharmacodynamic risk factors' for any pharmacodynamic risk factors.
- Use 'Specialist palliative care medicine prescribed' for any specialist palliative care medicine prescribed.
- Use 'Patient is on unnecessary medicines' for any patient is on unnecessary medicines.
- Use 'Pharmacist responsible for PCP' for any pharmacist responsible for PCP.
Table 9: Participants’ level of confidence in identifying and discussing needs assessments with patients or care providers

<table>
<thead>
<tr>
<th>Needs Assessment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients in pain</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>1 Patient on paracetamol/NSAID: verify dose/interval</td>
</tr>
<tr>
<td>2 Patient on tricyclic antidepressant/anticonvulsant: verify dose/interval</td>
</tr>
<tr>
<td>3 Patient on morphine: verify dose/interval</td>
</tr>
<tr>
<td>4 Patient receiving breakthrough pain analgesia: verify dose / interval</td>
</tr>
<tr>
<td>5 Patient on any fentanyl preparation: verify dose / interval/ advice on correct use and choice of brand</td>
</tr>
<tr>
<td>6 Patient on both strong and weak opioid</td>
</tr>
<tr>
<td>7 Patient on oral opioid and dose increased to &gt;50%</td>
</tr>
<tr>
<td>Disease or Treatment complications/adverse drug reactions</td>
</tr>
<tr>
<td>8 Patient suffering from opioid toxicity</td>
</tr>
<tr>
<td>9 Patient presenting with fever and/or sore throat (possibly neutropenic)</td>
</tr>
<tr>
<td>10 Patient is on bisphosphonates: monitor renal function, vitamin D and Calcium</td>
</tr>
<tr>
<td>11 Patient on benzodiazepine: verify use and duration (2-4 weeks)</td>
</tr>
<tr>
<td>12 Patient is at risk of drug interactions</td>
</tr>
<tr>
<td>13 Patient has mouth problems i.e. oral infection, xerostomia, stomatitis/mucositis, halitosis, excess salivation, swallowing difficulties</td>
</tr>
<tr>
<td>14 Patient suffers from nausea and vomiting</td>
</tr>
<tr>
<td>15 Patient suffers from GI problems like constipation, diarrhoea, bowel obstruction etc.</td>
</tr>
<tr>
<td>Miscellaneous (may require access to clinical records)</td>
</tr>
<tr>
<td>16 Patient has a pharmacodynamic or pharmacokinetic risk factor</td>
</tr>
<tr>
<td>17 Patient with involuntary weight loss &gt;5% in the last 6 months</td>
</tr>
<tr>
<td>18 Patient suffering from sleep disturbance</td>
</tr>
<tr>
<td>19 Patient’s renal function status in relation to drug choice and dose</td>
</tr>
</tbody>
</table>

*1 not at all confident, 2 not very confident, 3 neutral, 4 confident, 5 very confident.
2.3 Project Team Reflections and Learning

Reflections and Learning from Project Team

Each member of the team was asked to prepare a brief written reflective account of their journey over the first two years of the project. These accounts were then reviewed by the University team and analysed to identify a series of common themes. They are presented here to enable sharing and learning from these personal development journeys. The four themes identified address Project Framework, Project Implementation, Skills Development and Sustainability.

Project Framework

The team provided insight into various aspects of the Project Framework. Some Facilitators and the Project Lead commented on their experience of collaborating with the University team. Some initial reservations were resolved as the project progressed. There seemed to be an appreciation of the fact that the University team had taken the responsibility of producing the reports.

...I initially found it difficult... I felt that the research team didn’t fully appreciate the skills that the Macmillan team were bringing to the project ... I have found it easier to relate to the direction that the research team is taking...
(Macmillan Pharmacist Facilitator 3)

... After some initial tensions as the NHS and University teams got to know one another and worked out what each other’s expectations, skills and perspectives were ... (Project Lead)

The added benefit of engaging the University team to evaluate the project activity was, however, recognised:

.....I am certain this [independent evaluation] has been one of the strengths of the project, adding to the robustness of our methodology and the quality and breadth of the work (Project Lead)

Comments were made around the value that the Project Administrator had in coordinating several aspects of the project, and similar comments were made around
how the Project Lead was seen as a source of support and encouragement. Not only were they both seen as essential in the development of the Facilitators’ own personal skills, but the Administrator in particular was seen as a communications link between the four Facilitators:

...the project administrator has very ably done the majority of the work coordinating the various elements of the project action plan and responding to everyone’s queries, often when I am tied up in other work... (Project Lead)

...The project administrator has been a contact point and a great source of information...She has allowed the team to function together by sharing ideas and thoughts... (Macmillan Pharmacist Facilitator 1)

Some of the Facilitators commented on how diverse their backgrounds were from one another, and how this posed both challenges and opportunities as it meant that they brought different viewpoints to their role as Facilitators:

...The different minds together has truly resulted in much discussion covering a wealth of ideas and suggestions to improve patient care...Coming from a community pharmacy background and dealing with a variety of patients and carers has really helped in the development of my role...(Macmillan Pharmacist Facilitator 1)

The Facilitators were identified as key to informing the team about what was going on at ground level, with the Project Lead stating that they "brought us closer to understanding some of the underlying system and communication failures”.

Project Implementation
One of the challenges faced by all members of the team throughout the implementation of the project included the issues in engaging with one another. As the Facilitators only worked one different day per week, issues were experienced around coordinating with one another:
...I found difficulty keeping track of who worked when, who was doing what and even which email and telephone number everyone was using... (Macmillan Pharmacist Facilitator 3)

...The bigger tasks in the project which involve us all are difficult to co-ordinate due to the working patterns of the facilitators... (Project Administrator)

These time constraints had impacted on how they interacted with one another, as well as how they managed their work on a day-to-day basis:

... the lack of time to visit the pharmacies so far has meant I haven’t built up a strong enough relationship... (Macmillan Pharmacist Facilitator 2)

...Found planning ahead quite difficult ...There were times when there was far too much crushed into a small time period... (Macmillan Pharmacist Facilitator 3)

One Facilitator found it quite difficult to work to this restricted time frame due to the fact that they represented a very large CHCP, which also changed demographically through the course of the project. This Facilitator also found it difficult to make themselves known across the whole CHCP as a result.

Many of the Facilitators commented on their experiences of, and learning based around, engaging with Pharmacists and other members of the MDT. Frequently, the Facilitators felt that they faced challenges around this:

... Encouraging involvement of pharmacists in the wider aspects of pharmaceutical care... is both disappointing and a challenge... I created links with district nurse teams initially to identify local issues ...Raising awareness of the network amongst Care Home workers helped to reverse some misunderstandings about the network... (Macmillan Pharmacist Facilitator 4)
...I recognised the role of the practice manager and senior receptionist in communicating key messages and challenging misinformation about the network...
(Macmillan Pharmacist Facilitator 4)

Furthermore, one Facilitator commented on the influence they had on how network Pharmacists engaged with one another:

...I have managed to introduce the majority of the network pharmacists to each other... (Macmillan Pharmacist Facilitator 2)

Raising awareness of the network among health professionals was of paramount importance to the Facilitators. Learning points highlighted during the course of the project included how it may have been beneficial for the Facilitators to have led certain meetings in their CHCPs at some point.

Skills Development
All members of the team identified various skills that they had developed during the course of the project. The Project Lead articulated that the skills developed during participation in the NES Pharmacy leadership course proved very useful in securing the bid for the Facilitator project:

... Key skills I was able to refine and then successfully use in practice were influencing and negotiation skills... (Project Lead)

She had also witnessed the Facilitators develop their skills throughout the course of the project, and gain a better understanding of the project in relation to their own expectations and limitations:

...It was hard initially when everyone was so enthusiastic...I felt I was continually saying “not yet”... I think everyone has appreciated the importance of a structured, considered, approach...I have increasingly handed over responsibility to them...
(Project Lead)
The Project Administrator identified areas in which she developed her skill set throughout the course of the project:

...I have had to improve my working knowledge of Excel to produce a work plan for the project... preparing a workshop session takes a lot more work than I had realised...(Project Administrator)

Some of the facilitators commented on how they had to build on their knowledge of the various aspects of palliative care, as well as the infrastructure of NHS GG&C, and often drew from their own previous professional experiences to facilitate their learning:

...Challenges I faced in this role included adjusting to working for a large organisation and getting used to the layers of infrastructure (Macmillan Pharmacist Facilitator 2)

...I have developed my time management skills...initially I found this quite difficult... I have pushed myself to give more presentations and the practice has helped...My computer skills have also improved... (Macmillan Pharmacist Facilitator 2)

Another skill many of the Facilitators felt they had gained was the ability to coordinate and develop training schedules and materials:

...One of my achievements has been to initiate the community [pharmacy] support staff training days and involve the support staff to allow the palliative care network to function as one... (Macmillan Pharmacist Facilitator 1)

...one of my successes was developing the resource pack and encouraging community pharmacists on a face to face basis... (Macmillan Pharmacist Facilitator 4)

The facilitators recognised not only the benefits they received from developing training materials and facilitating on training days, but also the value that it had to the wider team in promoting the network and maintaining the messages that were being
communicated.

**Sustainability**
The Project Lead had a number of comments generally relating to the project and measures for sustainability. One of the key limitations was in relation to her post, and finding a balance with her other professional duties:

> ... One of my biggest concerns and a personal frustration has been trying to juggle the project with a wide range of other priorities which are integral to my role ... and not always being able to commit sufficient time to the leadership of the project...(Project Lead)

Upon reflection however, the Project lead identified that some contingency could have been put in place to “backfill” her main job while working on the project. Further comments were then made on moving forward with the project, and how best to build upon the work already completed:

> ...Maintaining momentum in the final year of the project will require commitment from us all... in a difficult financial climate, we have indeed been fortunate to secure the funding from Macmillan which has allowed us to hopefully improve the care our patients and their carers receive...(Project Lead)

One of the key strengths of the project, and points to consider when sustaining the project work was the training delivered and the training materials developed by the team:

> ... The training developed and delivered by the project team for community pharmacy support staff is one of the most exciting developments, and I think a key way forward to make systems more robust and allow pharmacists to focus on clinical aspects of care... (Project Lead)

It was clear from the reflections provided that although maintaining training would be challenging, it was key in maintaining the progress already accomplished.
2.4 Recommendations

The following recommendations have been drawn from the work undertaken in phase 2 and are presented as a guide to inform and shape discussions for the third year of the project.

Information resources

Patients / Carers
- Encourage community pharmacies to inform patients on changes in their medicines and work to raise patient and carer expectations of pharmacy services.
- Develop a written, easily accessible resource (to supplement verbal information) educating palliative care patients and their carers on accessing their medicines and information from their community pharmacy.
- Identify and promote a list of validated and reliable web-based patient information resources.

Community Pharmacy / Multidisciplinary Team
- Promote the sharing of resources generated through the project as tools to support best practice, through existing local and national networks.
- Assess the feasibility to move project resources developed to electronic platforms to facilitate resource sustainability.
- Continue to develop guidance for medicines used in palliative care, to support patient care.

Communication and networking
- Continue to establish and strengthen communication strategies across the CH(C)Ps both within pharmacy and across the multidisciplinary team, as appropriate.
- Assess how communication strategies can become more system dependent rather than person dependent, to facilitate sustainability.
- Identify the information, communication and support needs for care home staff to improve pharmaceutical palliative care for their residents.
- Maintain ongoing leadership, coordination and support from the Project Lead and Project Administrator to ensure communication between the project team and alignment of the project with local/national frameworks.
Skills development

Pharmacist / Pharmacy support staff

- Continue education sessions for pharmacists and pharmacy support staff across NHS GG&C to sustain core skills and develop enhanced skills within community pharmacy; these should be aligned to support registration requirements with the General Pharmaceutical Council
- Encourage experienced community pharmacists to assist with education sessions to promote local sustainability
- Future education sessions for pharmacy staff should be shaped by local educational needs assessment and key national priorities e.g. anticipatory care, supplementary/independent prescribing
- Develop e-learning tools for pharmacy support staff education modules with the support of NHS National Education Scotland
- Field test the designed pharmaceutical care plan with community pharmacists and establish the information technology steps necessary to support this through the evolving CMS
3. Phase 3: Evidence based model of community pharmacy palliative care services

3.1 Policy/Service Context

The Healthcare Quality Strategy for NHS Scotland, published in May 2010 provides a direction of travel for NHS Scotland with a central focus on person centred, safe and effective care [28]. This has been built upon with a more recent NHS Scotland Strategic narrative on “Achieving Sustainable Quality in Scotland's Healthcare: a 20:20 vision [29]. This narrative provides a continuing commitment to the values of collaboration and cooperation through partnership working across NHS Scotland, with patients and the voluntary sector to enable everyone to live longer healthier lives at home, or in a homely setting. It includes the actions to prioritise anticipatory care and provide support for people to stay at home/in a homely setting as long as this is appropriate and avoid the need for unplanned or emergency admissions to hospital. The Macmillan project fully aligns to the current policy direction focusing on supporting patients’ and carers’ palliative care needs within a community setting.

In Scotland in 2010/11 there were a total of 1,233 community pharmacies dispensing 87.6 million items, approximating to 71,046 items per pharmacy. Audit Scotland [2] estimated the number of palliative care patients, including those with non-malignant illness, with palliative care needs at 42,000. Relating this to community pharmacy services, this equates to approximately 34 patients per pharmacy per annum.

The Macmillan project has focused on four (CH(C)Ps) within NHS GG&C:

- South West Glasgow CHCP
- West Glasgow CHCP
- West Dunbartonshire CHP
- Inverclyde CHP.

Tables 10 and 11 illustrate the variable size and composition of the CH(C)Ps population and health service provision in 2010 at the commencement of the project.
Table 10  Population Overview [31]

<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 11  Health Service Provision [31]

<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>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 Pharmacies</td>
<td>8</td>
<td>9</td>
<td>5</td>
<td>4</td>
<td>26</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>

3.2  Service Delivery Model

The evidence base developed through design, delivery and review of the Macmillan project has been used to inform an evidence based model of practice.

Figure 2 provides a conceptual model of the proposed pharmacy services within the
palliative care framework. The model has at its centre the patient, and their family/carers, located within their communities and cared for at home by the primary care multidisciplinary team (MDT) including community pharmacy. These frontline community services are then supported by acute and specialist care including specialist pharmacists. The Managed Clinical/Care Networks (MCN) in each health board provide the framework within which community and specialist care is delivered.

**Figure 2 – Model of pharmacy services within palliative care framework**

Observation and capture of project activity over the period Jan 2010 to December 2011 has enabled a detailed analysis of community pharmacy clinical practice in support of palliative care to be undertaken. This has informed the construction of a series of key functions that are viewed as important to the delivery of effective pharmaceutical palliative care services within a primary care setting. These key functions can be aggregated under three key headings: community pharmacy; facilitator /interface; leadership and team co-ordination/administrative function.

**Community Pharmacy Function**
This can be divided into those services that all community pharmacies should deliver,
i.e. core service, and an enhanced service (table 12). The core service is aligned to the role of community pharmacy as defined within the evolving chronic medication service, part of the new community pharmacy contract.

The enhanced service builds on and extends the core service. This service has traditionally been developed through the establishment of community pharmacy palliative care networks within health boards, formerly as one of the Model Schemes in Pharmaceutical Care in NHS Scotland. In moving forward, definition of the functions will enable flexibility in delivery of services as local / national policy and strategy evolves to shape pharmacy and palliative care services.

**Table 12 – Community Pharmacy Functions**

<table>
<thead>
<tr>
<th>Core Service</th>
<th>Enhanced Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Clinical assessment of prescriptions</td>
<td>• Anticipatory care</td>
</tr>
<tr>
<td>• Consideration of preventable side effects</td>
<td>• Management of patient symptoms</td>
</tr>
<tr>
<td>• Counselling on medicines</td>
<td>• Out-Of-Hours Palliative Care service</td>
</tr>
<tr>
<td>• Prompt supply of medicines</td>
<td>• Maintain availability of agreed stock of Palliative Care medicines</td>
</tr>
<tr>
<td>• Signpost Community Pharmacy and additional services</td>
<td>• Investigate failures in medicine supply</td>
</tr>
<tr>
<td>• Liaise with MDT</td>
<td>• Provide advice on pharmaceutical palliative care to pharmacy colleagues and MDT</td>
</tr>
<tr>
<td>• Awareness of palliative care issues amongst the whole Pharmacy team</td>
<td>• Independent/Supplementary prescribing</td>
</tr>
<tr>
<td></td>
<td>• Appropriate referral if concerned about particular patients</td>
</tr>
</tbody>
</table>

*Facilitator/Interface Function*

In developing the role of the Macmillan Pharmacist Facilitator as part of the Macmillan project and examining the activities undertaken by these post holders it has been shown that there is a need for a facilitator/interface function to drive improvements in patient care (table 13). This provides further evidence to support the view from Audit Scotland (2) that local clinical leadership plays an important role in driving change at an operational as well as at a strategic level.
This project has clearly identified the importance of and demand for education provision to patients/carers to enable and empower them to access the information and services they require. The activity documented also quantifies the educational function necessary for community pharmacists, their pharmacy team and the wider multidisciplinary team including GPs, district nurses and practice managers to support safe and effective use of medicines. Recognition of the need for sustained training opportunities to address staff turnover, particularly of pharmacists in community pharmacy, was identified. Additionally, and at the centre of this facilitator/interface function is a focus on effective communication and collaboration both within and across care settings of healthcare professionals involved in palliative care services.

Table 13 –Facilitator/Interface Function

<table>
<thead>
<tr>
<th>Function</th>
<th>Activities</th>
</tr>
</thead>
</table>
| Information - Patients / Carers | - Help develop patient/carer information resources to support verbal information  
- Raise awareness of Community Pharmacy Services  
- Sign-posting to other services e.g. Macmillan Cancer Support |
| Education – Multi Disciplinary Team | - Education and training needs assessment  
- Development & delivery of training  
- Develop and update appropriate resources to aid safe use of medicines and symptom management  
- Improve availability of information on all medicines commonly used in palliative care  
- Provide advice to practitioners on clinical issues and resolution of problems |
| Communication / Collaboration | - Mapping of clinical services  
- Promote information sharing across Primary Care team to facilitate Pharmacy involvement in management of palliative care patients, and effective communication between pharmacies when required  
- Establish communication / care pathways between care settings |

_Leadership and team co-ordination / administrative function_

In delivering this Macmillan project through operating a sessional facilitator model it
has become evident that the success of this delivery model has had a clear dependency on clinical leadership and a coordinating/administrative function (table 14).

**Table 14 – Leadership and team co-ordination / administrative function**

<table>
<thead>
<tr>
<th>Leadership</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Vision</td>
</tr>
<tr>
<td>• Aligning with Health Board and national priorities for pharmacy and palliative care</td>
</tr>
<tr>
<td>• Clinical leadership</td>
</tr>
</tbody>
</table>

Team co-ordination / administration

| • Co-ordination of strategic planning and prioritisation of team activities enabling shared programme of work, where appropriate |
| • Design and preparation of resources and training materials |
| • Communication |
| • Sharing learning and peer support |

### 3.3 Capacity Planning Model

The evidence base for capacity planning within pharmacy palliative care services has, to date, been based on cancer services, with a focus primarily on activity within the acute/secondary care setting, providing guidance in relation to pharmacist resource necessary for hospital/hospice specialist services. The limitations and deficiencies of the capacity planning model drawn up in 2001 have been previously recognised, and include the needs of patients in non-cancer hospital settings and primary care [13]. There is no published work relating to primary care pharmacy services for palliative care within NHS Scotland.

The Macmillan project (through classification of the key functions of a successful community pharmacy service model) has provided the framework to generate a detailed mapping of the activities necessary to deliver these functions. This mapping has been completed using a standardized format (Toolkit) which has been drawn from a resource toolkit developed in Australia to support development and description of service models including palliative care. [30]

These tabulations combined with the experience of the project team have been used to
generate the following evidence based capacity plan for palliative care (table 15). Further modification of the capacity plan may be required as elements of work within the ‘future directions’ sections of the report are progressed in 2012. Testing of capacity predictions for the various functions at maintenance phase will also be required.

**Table 15 - Evidence based capacity plan**

<table>
<thead>
<tr>
<th>Function</th>
<th>Population / Community Pharmacy coverage</th>
<th>Human Resource / Contract Requirement</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Community Pharmacy Function</strong></td>
<td>Core service to local community</td>
<td>Scottish community pharmacy contract</td>
</tr>
<tr>
<td></td>
<td>Enhanced service to local community</td>
<td>Enhanced community pharmacy service payment (local / national agreement)</td>
</tr>
<tr>
<td><strong>Facilitator/Interface Function</strong></td>
<td>~100,000 population</td>
<td>Development / Start-up phase: 0.2 wte pharmacist</td>
</tr>
<tr>
<td></td>
<td>~ 30 community pharmacies</td>
<td>Maintenance phase: to be investigated</td>
</tr>
<tr>
<td><strong>Leadership and Team Co-ordination / Administrative Functions</strong></td>
<td>400,000 population</td>
<td>Development / Start-up phase: 0.2 wte clinical leader/management</td>
</tr>
<tr>
<td></td>
<td>~ 100 community pharmacies</td>
<td>0.4 wte administrative support</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Maintenance phase: to be investigated</td>
</tr>
</tbody>
</table>

**Conclusion**

The Healthcare Quality Strategy provides a direction of travel for NHS Scotland. This is contextualised for palliative care through “Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland”, published in October 2008, which 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 Argyll & Clyde Pharmaceutical Palliative Care Health Needs Assessment from which this Macmillan project was established. The Macmillan project fully aligns to the current policy direction focusing on supporting patients’ and carers’ palliative care needs within a community setting.

Evaluation of the project has provided the opportunity to observe, shape and record comprehensively the development of community pharmacy within a palliative care managed care network across a diverse mix of primary care settings within NHS GG&C. The evaluation output, delivered in two parts, has focused on:

- Characterising the baseline community pharmacy services across four project CH(C)Ps, and identifying key issues and gaps in current practice through qualitative and quantitative methods [31]
- Recording the activities and resources developed to improve clinical services for patients and carers through developing community pharmacy capacity and skills, and better integration within the multidisciplinary team; evolving an evidence based model of community pharmacy palliative care.

For NHS Scotland, the evidence from the project presents for the first time a conceptualised clinical practice model and capacity planning framework for community pharmacy palliative care services. The model aligns with policy frameworks in pharmacy to maximise the use of pharmacists’ professional competence in planning and delivering clinical services. The model provides detail of the key functions and activities important to support the safe and effective use of medicines for patients and their carers but provides this in a format that enables flexibility for the deployment of these functions through local business planning and service delivery frameworks.
Resource Toolkit

To access any of the hard-copy resources listed below, please contact the Project Administrator Carol Andrews via: carol.andrews@ggc.scot.nhs.uk or 01505 706873.

Palliative care resource folder (hard-copy)
Palliative Care Prescribing Aid
Communications Development exercise form
Facilitator diary/activity log
PostScript Bulletin (August 2010)
Community Pharmacy Matrix
Facilitator Role Matrix
Administrative Role Matrix
Leadership Role Matrix
References


Available from resource toolkit.


22 NHS Greater Glasgow and Clyde Pharmacy and Prescribing Support Unit: Team Brief, Issue 37, July 2011.

23 Refors L. Symptom control in palliative care associated with malignancy, the development and validation of a pharmaceutical care plan [Master’s dissertation]. Uppsala University; 2010.


