

ANNEX A – RESPONDENT INFORMATION FORM

A consultation on the provision of specialist residential chronic pain services in Scotland



RESPONDENT INFORMATION FORM

Please note this form **must** be returned with your response to ensure that we handle your response appropriately

1. Name/Organisation

Organisation Name

Marie Curie Cancer Care

Title Mr Ms Mrs Miss Dr Please tick as appropriate

Surname

Nicol

Forename

Bruce

2. Postal Address

14 Links Place

Edinburgh

Postcode EH69AD

Phone 0131 561 3902

Email

bruce.nicol@mariecurie.org.uk

3. Permissions - I am responding as...

Individual	/	Group/Organisation
<input type="checkbox"/>	Please tick as appropriate	<input checked="" type="checkbox"/>

(a) Do you agree to your response being made available to the public (in Scottish Government library and/or on the Scottish Government web site)?

Please tick as appropriate

Yes No

(c) The name and address of your organisation **will be** made available to the public (in the Scottish Government library and/or on the Scottish Government web site).

(b) Where confidentiality is not requested, we will make your responses available to the public on the following basis

Please tick ONE of the following boxes

Yes, make my response, name and address all available

or

Yes, make my response available, but not my name and address

or

Yes, make my response and name available, but not my address

Are you content for your **response** to be made available?

Please tick as appropriate

Yes **No**

(d) We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Please tick as appropriate

Yes

No

26th October 2013

Marie Curie's response to the consultation on the provision of specialist residential chronic pain services in Scotland.

1. Marie Curie gives people with all terminal illnesses the choice to die at home. Our nurses provide them and their families with free hands-on care and emotional support, in their own homes, right until the end. In Scotland we run hospices in Edinburgh and Glasgow, which provide free specialist medical care for those with serious illnesses, and emotional support for their families, giving them the best possible quality of life.
2. Marie Curie Cancer Care is pleased for the opportunity to provide feedback to the consultation on the provision of specialist residential chronic pain services in Scotland. Our response is based on our experience as a charity which specialises in end of life care and who regularly treats those with chronic pain issues, either directly or indirectly related to their life-limiting illness.

Marie Curie's experience of treating those suffering from chronic pain

3. According to The National Bereavement Survey (VOICES) 2011, patients who were asked about relief of pain and suffering reported that pain relief was being provided 'completely, all of the time' most frequently in hospices (62 per cent) and least frequently among those at home (17 per cent).
4. Marie Curie's Hospice outpatient services address pain management whilst we also provide a 4-week training programme for doctors on pain control in the palliative care setting at our Glasgow hospice. The course allows doctors to gain experience and to familiarise themselves with the services available. Glasgow's clinical team also hold a teleconference with chronic pain colleagues on a weekly basis to discuss palliative care patients with complex pain who may be amenable to interventions.
5. While the charity does not specialise in dealing with *chronic* pain, we are committed to the holistic care of our patients and chronic pain will routinely fall under our remit. Using a palliative care framework, these patients are assessed, treated and supported by a multidisciplinary team from diagnosis to death, which is usually a matter of days, weeks or months. Due to our expertise, we would not traditionally refer our patients to the Bath Centre for Pain Services.
6. At times however, chronic pain patients who do *not* have a terminal diagnosis may be referred to palliative care services. These patients are often referred for symptom management when all other interventions and support systems, including chronic pain involvement, have been exhausted.
7. Clinical staff noted their concerns over the use of a purely palliative approach to the management of those patients suffering with chronic pain who are not terminally ill. Feedback from clinical staff is that these situations are 'inherently complex' and often do not result in outcomes that are significantly beneficial to the patient. They advised that such treatment, at times utilising specialist palliative medication, may not be in the patient's best interests, and indeed may have the 'potential to do more harm than good'.
8. **Conclusion** – it is in the best interests of the patient for palliative care services to work in partnership with chronic pain services. There is much to learn from each other and a collegiate approach to assessment should ensure an effective approach to care and treatment.

Delivering a specialist chronic pain service for those with palliative care needs in Scotland considerations and recommendations:

Time

9. A particular challenge in end-of life and palliative care is time, and time wasted at the point of care can have significant consequences for patient, carers and health professionals. Decisions need to be made quickly, and care packages need to be implemented to support them to move them to an appropriate place to die, in line with their wishes.
10. **Recommendation** – there should be clear guidelines designed to ensure appropriate collaborative working with chronic pain specialists, for the right patient at the right time.

Access to appropriate/new medicines

11. Research has suggested that access to drugs and palliative care are not mutually exclusive, but can work together towards a common goal of extending life and ensuring a better quality of life at the same time. Research has shown that early access to palliative care can lead to significant improvements in both quality and length of life. However, many new medicines for extending the end of life often have severe and painful side effects, which palliative care services can support and help manage.
12. As an example, with regard to end of life care neuropathic pain (pain that comes from problems with signals from the nerves) is present in at least 50% of cancer patients who have pain which is difficult to control, however treatment is empirical, with no evidence to guide drug choice in individual patients. In addition, drug testing/analysis can take weeks, sometimes longer for 'adjuvant' drugs, (those that modify the effect of other agents). These factors mean that important time is lost for the patient with continuing poor pain control until the patient dies.
13. **Recommendation** Patients suffering chronic pain at the end of life should be able to access new medicines that would help extend their life.
14. **Recommendation** The appeal system for accessing new medicines needs to ensure that there is a fast track approach for those at the end of life whose time is limited.

Information sharing across all care settings

15. Communication is central to provision of quality care. Key to the success of any service (and the challenge) is to get the appropriate treatment to the appropriate patient at the appropriate time. As such, methods for sharing a patient's clinical needs and wishes are crucial to provision of quality end of life care. The

electronic Palliative Care Summary will now change to the Key Information Summary. This has the potential to ensure greater sharing of information on those palliative patients with chronic pain needs and should enable anticipatory care planning.

16. Pharmacists play a key role in the long-term management of patients with chronic disease. They are often seen as the first port of call for advice on their medicines and underlying health problems and can interact with the patient as often as a member of a general practice. In addition, pharmacists will come into regular contact with carers, families and those people who may not feel comfortable contacting their local general practice.
17. Patient/carer consent to the sharing of relevant information and contact details of patient's regular pharmacist should be included in palliative care registers; key information summaries; and care plans. This will improve communication and will help to identify possible sufferers of chronic pain.
18. **Recommendation** – An integrated approach to sharing patient's information on chronic pain is required so that it is readily available to carers; clinical teams in the acute setting; general practitioners; pharmacists; hospices etc This is crucial to delivering end of life care. Such an approach must be backed up by effective protocols and procedures and appropriate technology, including the use of telemedicine. Such approaches may also help to inform anticipatory care plans.

Capacity

19. There has long been an issue in regard to the capacity of chronic pain services to accommodate the numbers of patients they are referred. Due to advances in oncological treatment, Marie Curie are now involved with patients who have incurable cancer but longer disease trajectories. For example women with bone tumour/growths from breast cancer can survive up to ten years so there may be some overlap in services.
20. Specialist palliative care services are sometimes referred patients with chronic pain after curative cancer treatment because the waiting time for an outpatient appointment at the pain clinic is often over 6 months. It would be more appropriate for them to be seen by chronic pain services.
21. **Recommendation** We would welcome a review of waiting/times for those referred with chronic pain in order to test the appropriateness of referral.

Advocacy

22. With an estimated 0.3% of those suffering with chronic pain making it to secondary care, there is a clear need to provide them with a 'voice'. Chronic Pain sufferers may need help to navigate their way through welfare reform for example, to question decisions on eligibility for referral through their local NHS

Board or maybe to highlight a blockage in their route to receiving appropriate care.

23. **Recommendation** We would welcome Government feedback on how a specialist Scottish chronic pain service would be evaluated, on what key indicators and by whom.
24. **Recommendation** Clear criteria on eligibility for chronic pain services must be applied consistently across Scotland. Education on chronic pain and possible options for referral is required across general practices.

Scottish centre of excellence or roving service?

25. When considering a specialised chronic pain service in Scotland, we must be aware of the impact of the integration of health and social care services. If care is to be delivered at a local level in the future it would seem obvious to approach the provision of specialist chronic pain services in the same way. However, the resource and funding implications to provide a local service may not be justified by the numbers of patients for whom it may benefit.
26. According to the Scottish Government, of the 800,000 people in Scotland living with chronic pain, 20-30 are annually referred to the residential service in Bath. This throws up the question of whether providing centralised residential care in Scotland is cost effective when a suitable service is already available in the UK. Another point we would make would be that, if a centre of excellence is created in Scotland, the problem of travel to the centre would remain prevalent, exacerbated by the requirement on patients to pay travel costs up front.
27. **Recommendation** A Scottish centre for pain services should be complimented by a mobile service with the capacity to contact central specialist/experts using telemedicine and other online forms of communication.
28. **Recommendation** A Scottish centre for pain services would need to consider the practicalities of delivering intensive, two to four week programmes such as those in Bath. For example, dietary needs and accommodation requirements of disabled carer's and loved-ones must be taken into consideration along with the patients needs before their visit.
29. **Recommendation** Part of the centre's remit should be specifically set up to deliver training programmes designed to support health practitioners at a local level and reach all patients across Scotland. It is vital to provide a local service to those patients who cannot travel for intensive courses at a Scottish centre. Training would not only be provided by the NHS but should utilise the knowledge of those providing specialist health services such as palliative and end of life care. This would promote joint working and the benefits of communication between care providers whilst reducing waiting times.

Palliative care and chronic pain, a partnership approach

30. As touched on previously, it is important for palliative care services to work in partnership with chronic pain services. Effective collaboration, consistency of education from university to clinical leads, information sharing and sharing of expertise where appropriate will ensure patients receive quick and effective treatment in the appropriate place of care.

Marie Curie Cancer Care would be happy to discuss our response further if necessary.

Please contact

Bruce Nicol
Policy and Public Affairs Manager, Scotland
0131 561 3902
bruce.nicol@mariecurie.org.uk