

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

Breast Cancer Care

Title Mr Ms Mrs Miss Dr **Please tick as appropriate**

Surname

Carroll

Forename

Liz

2. Postal Address

Breast Cancer Care

Robertson House

152 Bath Street

Glasgow

Postcode G2 4TB

Phone 07921 125074

Email liz.carroll@breastcancercare.org.uk

3. Permissions - I am responding as...

Individual

/

Group/Organisation

Please tick as appropriate

(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**

About Breast Cancer Care

Breast Cancer Care is the UK's leading provider of information, practical assistance and emotional support for anyone affected by breast cancer. For over 30 years we have brought people together, provided information and support, and campaigned for improved standards of care. We use our understanding of people's experience of breast cancer and our clinical expertise in everything we do.

Breast Cancer Care has had a professional staff base in Scotland since 1989. We provide services for people with a diagnosis of breast cancer, Moving Forward self-management survivorship courses, information points in hospitals, information sessions on a range of topics, hair loss advice and support, support for Living with Secondary Breast Cancer services and host Younger Women's Forums. We run Breast Health Promotion Workshops. We also have a fundraising, events and volunteer management staff in Glasgow.

Our vision is that every person affected by breast cancer will get the best treatment, information and support throughout their experience of breast cancer. We reach many thousands of people every year through a wide range of services, including peer support provided by our many volunteers. Our network of Breast Cancer Voices across the UK (a group of people affected by breast cancer) share their experiences and expertise to inform our work. 33 of our Voices live in Scotland. We also work closely with health and social care professionals to support the delivery and planning of excellent patient care. Last year we were contacted nearly 2.4 million times by members of the public accessing our services.

Consultation response

Question 1: We would like to know in what context you are responding. Please choose one of the following:

I am responding as:

- a) an individual who experiences chronic pain
- b) a family member or carer of someone who experiences chronic pain
- c) a health professional
- d) an organisation representing people who experience chronic pain
- e) other stakeholder (please tell us in the comments box below)

Question 2: Please choose your preferred option (Chapter 2 provides details).

- Option 1 – a centre of excellence in a single location

Option 2 – a service delivered by local chronic pain clinicians (supported by other clinical advisors in another part of the country)

Option 3 – a service delivered in different locations (by a team of chronic pain specialists – an outreach or roving service)

Please tell us why this is your preferred option in the comments box below. The factors listed in Chapter 2 of the consultation paper may help you.

Pain often interferes with everyday tasks and by affecting sleep it can be an added source of anxiety at a time when clients are hoping to move forward in their recovery. Clients experiencing chronic pain may contact their hospital team to discuss the pain and ways to help relieve it. If they are to be referred to a pain clinic, it is important that there is strong expertise available in Scotland. A multi-disciplinary staff team is also a strong point in supporting this option, cancer patients may have varied and complex treatment needs and the support of MDTs is crucial. There is also an element of peer support in Option 1 which our clients tell us they find very beneficial. Option 2 has its merits but it lacks the clear advantages of having a Centre of Excellence in Scotland. We welcome the commitment to improving local services which will be complementary to a national center.

Question 3: Are there any of the options you disagree with? (If No, move straight to Question 4.)

If yes, please tell us which one(s) in the comments box, and why?

We have concerns about Option 3 in that it's not a tried and tested method of service delivery. It isn't clear from the description whether the patients might end up waiting some time if the delivery team are working in another area. For patients with a cancer diagnosis who are in chronic pain this would be unreasonable.

Question 4: If you have other ideas that have not been covered, please tell us about these in the comments box below. You may want to include the advantages and disadvantages of each.

Comments (box expands with text input - there is no word limit)

Question 5: What do you think the barriers are to accessing a residential pain management service? (For example, distance away from family, work or family commitments, upfront travel costs.)

Please list as many as you wish in the comments box below and include any others that are important to you.

Travelling to a residential service will not be an easy decision for a patient to make but with evidence from Bath suggesting improved outcomes they may be encouraged to do so. Being able to go with a carer/support provider can also make a big difference as it lessens the sense of isolation that is often experienced post treatment.

Question 6: Please choose from the list below which aspects of residential pain management services should be included in a Scottish service.

(choose as many as apply)

- A chronic pain assessment
- Supported one to one sessions to teach coping skills
- Group sessions
- Residential accommodation
- Opportunity for immediate carer/support provider to accompany patient
- Peer support
- Tailored exercise programme
- Medication assessment
- Other (please tell us in the comments box below)

Our clients tell us that these are the kinds of support they find helpful. Given the geography of Scotland, even having a Scottish Centre would entail long travel distances for some patients who may well need to have a carer with them. This underlines the importance of improving the local support available in primary and secondary care for people who are unable to travel or need to continue their treatment after the residential period so ideally would have a 2 pronged approach

Question 7: Irrespective of the final service model selected, should access to the current service provided in Bath (or elsewhere in the UK) be retained for occasional use?

Yes No Don't Know

Question 8: Have you previously attended, or supported someone attending a residential service outside Scotland?

Yes (please answer Question 9)

No (please move straight to Question 10)

Question 9: If you have attended, or supported someone attending a residential service outside Scotland, please tell us about any advantages and disadvantages of the experience.

Comments (box expands with text input - there is no word limit)

Question 10: If you, or someone close to you, has been offered but declined a residential service outside Scotland what were the reasons for this?

Comments (box expands with text input - there is no word limit)

Question 11: If you wish to add any further comments on issues raised in the consultation paper or current chronic pain services in Scotland, please use the comments box below.

This can be a seriously debilitating issue for our client group and given that there are two specialist centres in England and one in Wales, it is important that the same standard of care is available more locally in Scotland and we welcome this initiative.