

## Cancer Patient Experience Quality Performance Indicator Engagement Document

### Comments Form

We welcome your views on the draft Cancer Patient Experience QPI Engagement Document, in particular comments on:

- The appropriateness of the QPIs and measurement tools that have been developed.
- Key points or areas that are not covered within the engagement document or QPIs.

All comments are welcome, whether they be on all or part of the QPIs and are positive or negative. Comments can be submitted anonymously however we would be grateful if you could provide contact details, should any further clarification on comments be required.

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### **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 40 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 survivorship self-management courses, information points in hospitals, information sessions on a range of topics, hair loss advice and support, 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.

Please return via e-mail to: [cancerqpi@scotland.gsi.gov.uk](mailto:cancerqpi@scotland.gsi.gov.uk) by **Friday 25<sup>th</sup> October 2013**

**Feedback and Comments on QPIs: -**

QPI		Comments (please provide supporting evidence where appropriate)
1	Communication	We welcome the focus on high quality communications but believe the guidelines need to be more specific in what is required. Patients should also feel able to talk about body image and sexual problems, and feel their concerns were not just listened to but acted upon.
2	Information	<p>We are concerned about the lack of clarity regarding patients who do not speak English well. NICE cg 138 clearly states that issues around speaking English are addressed.</p> <p>Will HCPs be given specific training on communicating with patients who have learning difficulties?</p> <p>We welcome that a named nurse should be readily available at all stages of disease management. Clients continually tell us that having access to the same Breast Care Nurse throughout their treatment was particularly helpful. We think this should have consistency and be the same person throughout treatment and it is essential patients with both primary and metastatic cancer have access to a specialist nurse who has specialist training. We know from extensive research and patient consultation that patients with metastatic disease report poorer experiences and often link this to lack of access to a BCN who has specialist training in metastatic breast cancer . Information on our work in this area can be found here <a href="http://www.breastcancercare.org.uk/campaigning-and-volunteering/campaigning/current-campaigns/spotlight-secondary-breast-cancer/backg-0">http://www.breastcancercare.org.uk/campaigning-and-volunteering/campaigning/current-campaigns/spotlight-secondary-breast-cancer/backg-0</a></p> <p>We are concerned that there is no requirement or question asking if a patient is given information about support available outside the NHS for example expert charities and local support. Many patients benefit from support and information that is not available on the NHS. Having an approved list of charity partner's professionals can refer to can be beneficial, with a requirement to inform patients of their services. Being given information on who to contact locally for support gives both the health professional and patient confidence in the quality of the service provided.</p>

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QPI		Comments (please provide supporting evidence where appropriate)
3	Shared Decision Making	We welcome the commitment to shared decision making and the proposed measures.

**Feedback and Comments on Measurement Tools: -**

Measurement Tool		Comments (please provide supporting evidence where appropriate)
1	Communication	<p>It is quite a long questionnaire with 35 questions, some patients may find this quite daunting at what for them may be a very difficult time.</p> <p>Is it the intention that the form will be self completed or the questions asked by HCPs? Will this be consistent across NHS sites? It is recommended this must be completed by the patient to ensure concerns about on-going care do not influence responses.</p> <p>We have concerns as stated above about measuring patient experience for people with learning difficulties or language problems.</p> <p>There is very little space for additional comments on the form; this may discourage people from adding their views.</p>
2	Information	
3	Shared Decision Making	

**Any further comments:**

We very much welcome this step in improving quality and measuring patient experience across Scotland . We recognise the importance of this commitment and believe it will be a positive step for patients.

We believe that in section 1.1.2 where stages of the patient pathway where experience should be monitored should also include at a diagnosis of recurrence or metastatic disease and at least once more during treatment for recurrence/metastasis – as we know these patients report poorer supportive care and experience. Without this explicit recommendation this patient group will be overlooked.

The engagement document clearly states on page 3 (1.1) that this will be underpinned and supported by a programme of regional and national reporting. However it appears from Section 1.1.2 on page 4 that NHS Boards are not required to submit the actual data and analysis but to submit evidence that the experience has been measured and resulting actions progressed. We consider it important that the actual data is analysed at regional and national level so that overall standards and changes over time can be monitored. We think it is crucial that overall standards of performance and quality are agreed and assessed at local, regional and national level. This is particularly important in terms of taking account of the different stages of the patient pathway when experience has been measured and also the variety of NHS Board sites where patients are seen.

We welcome the detailed development process for these QPIs particularly the field testing and patient involvement in focus groups across Scotland. It is unfortunate that the groups scheduled for Aberdeen and Inverness had to be cancelled as it is not clear whether the views of patients from remote and rural areas will have been covered sufficiently in the other groups. Key issues reported by patients included the importance of having a specialist nurse to talk to, consistency in the point of contact and possible meetings with the MDT.

More detailed guidance should be given on how Health Boards should demonstrate how the patient experience has been measured and the actions taken to address any themes emerging from the data. There should be guidance on the time from survey to publication of results for Health Boards.

We are concerned that there is no information on what will happen if Health Boards report poor patient experience and improvements are not shown to have been made. For Health Boards reporting significantly poor patient experience waiting 3 years for a repeat survey seems too long. We suggest any poor outcomes should be addressed and reassessed at least every two years.