

Breast Cancer Care's response to 'Integration of Adult Health and Social Care in Scotland'

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, information points in hospitals, information sessions on a range of topics, hairloss advice and support, support for Living with Secondary Breast Cancer Groups 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 Questions

The case for change

Question 1: Is the proposal to focus initially, after legislation is enacted, on improving outcomes for older people, and then to extend our focus to improving integration of all areas of adult health and social care, practical and helpful?

Yes No

It is estimated that almost 10% of the total female population over 65 years of age is living with a diagnosis of breast cancer.¹ As the leading breast cancer support and information charity in the UK, we are concerned that many older women may not be receiving the level and type of support, treatment and information they need. We want to ensure that our own services and information meet the needs of this group, as well as working with others to improve this situation at all levels of

¹ Maddams, J.; Brewster, D., Gavin, A., Steward, J., Elliott, J., M Utley, M. & H Møller, H. (2009). 'Cancer prevalence in the United Kingdom: estimates for 2008', *British Journal of Cancer*, 101(3), pp. 541-547.

delivery.

Outline of proposed reforms

Question 2: Is our proposed framework for integration comprehensive? Is there anything missing that you would want to see added to it, or anything you would suggest should be removed?

Yes No

A comprehensive person-centred approach would also require a joined up approach to support in the areas of finance and money, accommodation, education and training, work and occupation.

National outcomes for adult health and social care

Question 3: This proposal will establish in law a requirement for statutory partners – Health Boards and Local Authorities – to deliver, and to be held jointly and equally accountable for, nationally agreed outcomes for adult health and social care. This is a significant departure from the current, separate performance management mechanisms that apply to Health Boards and Local Authorities. Does this approach provide a sufficiently strong mechanism to achieve the extent of change that is required?

Yes No

In theory, this should be an improvement although a view from the voluntary sector is that in Northern Ireland, health and social care are not noticeably more joined up as a result of being the responsibility of a single Department.

Question 4: Do you agree that nationally agreed outcomes for adult health and social care should be included within all local Single Outcome Agreements?

Yes No

It is essential that these nationally agreed outcomes measures are based on robust evidence and are developed in full consultation with voluntary sector providers, and patient and carers representatives. It is important that any nationally agreed outcome takes into consideration the need to reduce health inequalities.

Governance and joint accountability

Question 5: Will joint accountability to Ministers and Local Authority Leaders provide the right balance of local democratic accountability and accountability to central government, for health and social care services?

Yes No

Question 6: Should there be scope to establish a Health and Social Care Partnership that covers more than one Local Authority?

Yes No

Scottish local authorities differ widely in size and demographic range, there may be scope for combining smaller authorities especially where regional cancer services are provided by a Health Board covering a wider area.

Question 7: Are the proposed Committee arrangements appropriate to ensure governance of the Health and Social Care Partnership?

Yes No

The proposals stop short of including carers as members of the partnership committee. This is a change from the current commitment to include carers on Community Health Partnerships and the recognition of carers as **equal partners in care** in Scotland's Carers Strategy. Family members of people diagnosed with breast cancer as well as patients themselves should be represented. Voluntary sector providers, patients groups and carers organisations should be part of governance.

Question 8: Are the performance management arrangements described above sufficiently robust to provide public confidence that effective action will be taken if local services are failing to deliver appropriately?

Yes No

Yes, if Committee membership is widened as in question 7 above.

Question 9: Should Health Boards and Local Authorities be free to choose whether to include the budgets for other CHP functions – apart from adult health and social care – within the scope of the Health and Social Care Partnership?

Yes No

The scope of the Partnership should reflect local need.

Integrated budgets and resourcing

Question 10: Do you think the models described above can successfully deliver our objective to use money to best effect for the patient or service user, whether they need “health” or “social care” support?

Yes No

Yes, if it addresses the problem of ensuring care packages are in place when a patient is discharged from hospital.

Question 11: Do you have experience of the ease or difficulty of making flexible use of resources across the health and social care system that you would like to share?

Yes No

The care pathway of those with progressive, incurable breast cancer is ill-defined with little evidence of GP or primary care involvement leading to poor quality of life and a poor experience of care².

Breast Cancer Care's work on older women and breast cancer highlighted that older patients can face difficulties in accessing practical support to help maintain their independence and cope at home during and after breast cancer treatments. Older women affected by breast cancer have varied information and support needs around emotional, body image-related, and practical and financial issues, and these need to be identified and addressed through both health and social care services³.

Question 12: If Ministers provide direction on the minimum categories of spend that must be included in the integrated budget, will that provide sufficient impetus and sufficient local discretion to achieve the objectives we have set out?

Yes No

This should ensure that a minimum acceptable level of budget is available but might need to be reviewed in the light of experience

Jointly Accountable Officer

Question 13: Do you think that the proposals described here for the financial authority of the Jointly Accountable Officer will be sufficient to enable the shift in investment that is required to achieve the shift in the balance of care?

Yes No

Question 14: Have we described an appropriate level of seniority for the Jointly Accountable Officer?

²Reed, E., Simmonds, P., Haviland, J., Corner, J. (2011). 'Quality of Life and Experience of Care in Women With Metastatic Breast Cancer: A Cross-Sectional Survey.' *Journal of Pain and Symptom Management*. Vol. 43 No. 4 April 2012

³ Breast Cancer Care (2011) *Improving outcomes and experiences for older women with breast cancer Policy Briefing* (Supported by Age UK)

Yes No

Professionally led locality planning and commissioning of services

Question 15: Should the Scottish Government direct how locality planning is taken forward or leave this to local determination?

Yes No

Given the diverse nature demographically of the localities in Scotland, this should be left to local determination. Representatives of voluntary sector providers, and carers and patients associations should be involved.

Question 16: It is proposed that a duty should be placed upon Health and Social Care Partnerships to consult local professionals, including GPs, on how best to put in place local arrangements for planning service provision, and then implement, review and maintain such arrangements. Is this duty strong enough?

Yes No

The answer to this is rather dependent on the outcome of the discussions on the scope of the GMS Contract in Scotland.

Question 17: What practical steps/changes would help to enable clinicians and social care professionals to get involved with and drive planning at local level?

There should be one managerial structure for an integrated health and social care workforce to ensure a cohesive and collaborative approach to care.

Question 18: Should locality planning be organised around clusters of GP practices? If not, how do you think this could be better organised?

Yes No

Again this will depend on GP contracts as in Question 16 above.

Question 19: How much responsibility and decision making should be devolved from Health and Social Care Partnerships to locality planning groups?

This depends crucially on the level of support and resources available to the locality planning groups. We would support local decision making where possible.

Question 20: Should localities be organised around a given size of local population – e.g., of between 15,000 – 25,000 people, or some other range? If so, what size would you suggest?

Yes No

Putting specific size ranges may not work in certain geographical areas, it should be community based rather than numbers based.

Do you have any further comments regarding the consultation proposals?

In general we are supportive of the proposals. The essential key elements are integrated budgets, integrated operational and strategic plans and staff who are skilled in working across disciplines. The relevant workforce needs a full understanding of the full range of health and social care issues and interventions. This requires leadership which is well outlined in the proposals.

Do you have any comments regarding the partial EQIA? (see Annex D)

The EQIA seems very comprehensive and supports the proposal's emphasis on prioritising older people as they are more likely to have long-term conditions and from our perspective, older women are one of the groups who are more likely to have a diagnosis of breast cancer.