

Tools and techniques for ongoing patient involvement

Bringing the patients' voice to managers and commissioners can have a powerful effect when you are looking to develop and improve services. The views and experiences of your patients can and should inform how your service is delivered and developed on an ongoing basis. Having a mechanism for regularly seeking feedback from people with secondary breast cancer being treated at your hospital can:

- Give you a mechanism for checking that any actual or planned changes have the desired impact
- Provide evidence to strengthen your case for any additional resource or changes to working practices
- Establish an ongoing focus on service improvement
- Maintain the visibility of patients with secondary breast cancer

How this works and what it looks like though can be very different depending on a number of factors including:

- Number/ nature of patients wanting to be involved
- How well established your service is and the scale of any likely changes or developments
- Capacity of nurses/ other staff to support patient involvement
- Other existing patient forums

Whatever you set up needs to be designed pragmatically with local resources and circumstances taken into account. However the following options may prove a useful starting point for identifying what will work:

- 1) Ensuring patients with secondary breast cancer are represented on any existing Patient Experience Group or Committee – this might mean you approach one of more patients who are keen to influence service improvement and encourage them to participate.
- 2) Establishing a regular (for example quarterly or annual) patient forum where all patients with secondary breast cancer are invited in to discuss the patient experience with nursing staff, what's working and where there's room for improvement. This might include a market place and other information for patients too.
- 3) Setting up and facilitating a patient group (which you will need to regularly recruit new members to) which meets regularly with the nurses with a focus on service improvement within the hospital (NB this is not a support group).
- 4) An annual survey to patients.
- 5) An annual patient focus group.
- 6) If there is an existing support group or Breast Cancer Now Living with Secondary Breast Cancer service, linking in with this and either attending once a year or inviting members to meet with hospital staff to discuss patient experience.