

Good practice.

The summer school heard three talks giving examples of good practice.

Adrienne Morgan spoke about her experience in setting up the NCRI Breast Clinical Studies Group (BCSG) Symptom Management Working Party.

She explained that symptom management had not been examined in this way, despite the need for this. ICPV members had been involved on the Breast CSG for many years, and knew that clinicians valued patient involvement in this way.

Adrienne explained that she suffers from symptoms as a result of her treatment for breast cancer. These include severe and frequent hot flushes and sexual dysfunction. She attended the UK Breast Intergroup meeting in 2009, together with about 200 delegates, and following on from this she met with Carlo Palmeri (clinician) and Jenny Quantrell (metastatic breast cancer patient sadly now dead), who were keen to set up clinical trials for metastatic breast cancer, she attended UK Breast Intergroup meetings regularly, and she worked as a patient advocate on the Breast Cancer Campaign Tissue Bank.

These contacts led to Adrienne being invited to speak at a Royal Society of Medicine meeting, where she met researchers working in hot flushes. She became aware of a study which concluded that many patients discontinued taking tamoxifen due to severe symptoms such as Adrienne's. This research and her contacts made Adrienne realise that there was a need for co-ordinated research into the problems of symptoms. In 2012 she was appointed to the BCSG and discovered that symptom management was rarely discussed. She decided a working group was needed and, with the support of the BCSG, she contacted interested people and established the working party. The working party has completed surveys on hot flushes of health professionals and patients, presented posters at international meetings, written a paper and generally raised the issue of symptom management.

She is planning a workshop, funded by Breast Cancer Campaign (BCC), who supplied the secretariat, of all those working on mammalian vasomotor symptoms.

In reply to questions, Adrienne explained that all the CSG Working parties had to arrange their own secretariat, so was grateful for BCC's offer to do this. She was applauded for her efforts in setting up the working party, which other groups are now using as a model.

Carolyn Morris spoke on good practice on a collaborative approach to patient follow up after cancer treatment.

ICPV was invited by Charlotte Coles to submit a paper to the journal Clinical Oncology about patient experience of life following cancer diagnosis- what needs did they have; were these clinical needs or a comfort blanket? In collaboration with Maggie Wilcox, Mairead Mackenzie and Adrienne Morgan, a questionnaire was designed to establish patients' experiences of follow up, and what they thought of other possible models. The questionnaire was sent to several organisations- including the NCRI Consumer Liaison Group, Cancer 52, the Rarer Cancers Group, and local groups

110 Replies were received from patients with eleven cancer types, 68% female, 32% male.

Sophie Gasson led on writing up the results of the questionnaire as a journal paper, with assistance from Carolyn, Lesley, Hillary, Adrienne and Mairead. The time from submission to acceptance was very good. Carolyn urged all involved to read the paper, and suggested that there was scope for further work on establishing who should be contacted in the event of a further questionnaire being devised.

The main need now was to mine the information gathered by the questionnaire- there being more responses than could be summarised in the paper. Annie Young, a cancer nurse, Janet Dunn from Warwick and Carolyn were keen to do this.

There had been good feedback from professionals (e.g. a surgeon who indicated how shocked he was to discover patients' reactions to treatment). Mairead Mackenzie added that there had been positive feedback from Breast Cancer Care, with whom ICPV would maintain contact.

Hilary Stobart talked about consumer involvement with CT Rad, the NCRI Clinical and Translational Radiotherapy Research Working Group.

Although called a working group, it in fact has 82 members, including six consumers and numerous subgroups and clinical trials. Radiotherapy research is particularly dependent on dialogue between multiple disciplines, which CTRad has successfully nurtured. Previously, the UK was lagging behind the rest of Europe. As a result, it has produced a number of new initiatives, including RADCOM and RADCAS. CTRad has helped deliver and nurture academic centres with adequate posts- the number of University chairs has increased from three to six- and activity in radiobiology and radiotherapy, and has supported quality assurance initiatives (the RTTQA group). Much more work is planned in the future.

Consumer influence has grown. The initial aim was to have two consumer members on each workstream, each with a scientific mentor. At first there were numerous challenges, such as not always having a full complement of consumer members, and it was difficult to see how to make the consumer role effective in some workstreams.

New ways of working have therefore been developed as a result of initiatives taken by consumers, such as regular consumer meetings, a new statement of core roles, expectations and working models for consumer involvement. All consumers are involved at Proposal Guidance and other all-workstream meetings, the mentoring regime has been improved, and there is now regular attendance by consumers at offshoot meetings arising from CTRad.

These changes have enabled improved consumer feedback, co-ordination and support and more efficient use of consumers' time.

It was noted from the floor that CTRad had been set up following concerns that radiotherapy was 'old fashioned' compared to pharmaceutical therapies, and that changes

in the CTRad structure had been dependent on consumer involvement. Clearly, work had to continue to ensure that radiotherapy research and practice were improved.

Chris Finch, ICPV Trustee