

Abstract No. B103 NCRI Conference November 2011
Title **Independent Cancer Patients' Voice - speaking clearly and being heard**
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Background

Independent Cancer Patients' Voice is a patient advocate group led by patients for patients. We were started two years ago by cancer patients with a keen interest in research and in improving outcomes for future patients. Most were active locally and nationally and had already been actively involved with breast cancer charities, three were members of the NCRI Breast CSG. They came from a wide range of professional backgrounds and patient experience and had received differing levels of training, mentoring and support as advocates. Several had undertaken the specialist Project LEAD training provided in the USA by the NBCCF.

Method

Education, mentoring and peer support for patient advocates to bring the views and experience of cancer patients, their family and carers, to the cancer research community.

Results

We have held study days at Leeds, Velindre, Barts' & The London and at the House of Lords. These benefit patients and also researchers who enjoy our frank, open and lively discussions. Academics are keen to present new trials for discussion and scrutiny. We supply and mentor patient members of trial management and other working groups, have written effective letters of support for clinical trials and to ethics committees. Our members attend and speak at cancer conferences. We contribute to consultations and have a very active Google group.

Conclusion

We believe we are an exciting and novel new partner in cancer research in the UK. Although started by breast cancer patients, we always planned to become generic and we now enjoy the contributions of non-breast patient members. We have received some extremely valued affirmation from cancer researchers and became a registered charity last year.

Acknowledgements

We would like to thank all the academics, clinicians and cancer patients who make the work of ICPV possible.

References

www.independentcancerpatientsvoice.org.uk