

Quality Advocacy needs Quality Education

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ICPV, who we are

Independent Cancer Patients' Voice (ICPV) is a patient advocate group led by patients for patients. We bring the views and experience of cancer patients, their families and carers to the cancer research community. Our mission statement is that clinical research is improved by patients being partners with clinicians and healthcare professionals, rather than passive recipients of healthcare. Members of ICPV are actively involved in many areas of research. To facilitate and enhance our role in these activities, members aim to understand the fundamentals of cancer, study design and current areas of controversy and research.

What we do

Working with the internationally renowned Barts Cancer Institute we have developed a tailor-made course which provides a week-long intensive training in basic cancer biology, introduction to research terminology and study design, and critical evaluation of research proposals and scientific papers. This course VOICE (Vision On Information, Confidence and Engagement) Science for patient advocates is unique, the only course of this type in the UK.



Purpose of the course



To date, patients have had very little involvement or experience of laboratory based research which can cause challenges for patients and carers, who often have a limited understanding of cancer biology. Researchers at BCI and members of ICPV therefore worked in partnership to develop a 5 day training course for cancer patient advocates which aims to lead patients through the research process beginning with basic biology, through to experiments in the lab and on to discussing clinical trials. In addition to attending lectures and performing experiments participants were able to meet and speak with cancer scientists. We believe that this project is the first of its kind in the world to offer people affected by cancer an opportunity to spend time in laboratories in order to build a practical understanding of cancer biology.

Conclusion

Following a successful pilot course in 2013, early feedback from VOICE 2014 confirms that participants are more confident about discussing laboratory based research in their roles as advocates having gained a better understanding of how work is done by laboratory-based researchers. An additional impact is that scientists who were involved in the course have been both motivated and inspired by their contact with participants.



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For more information see

<http://independentcancerpatientsvoice.org.uk/voice-science-for-patient-advocates/>