

The Voice Newsletter

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ICPV's Poster on Patient Involvement in Tissue Banking presented at the NCRI Cancer Conference in November 2013 and the San Antonio Breast Cancer Symposium in December 2013

The idea of creating ICPV came from Daphne Havercroft, Jill Bartrop and Maggie Wilcox when they were lay members of the NCR Breast Clinical Studies Group, and Adrienne Morgan assisted with its establishment. They invited a few other breast patients to join them in a Camden pub to discuss idea of forming an independent group. Although all breast patients, their aim was to become a generic cancer group and ICPV now has members from many tumour groups and collaborates with Cancer52, Rarer Cancer Foundation, Brainstrust, as well as other charities. They felt strongly that there was a need for a patient-led organisation to bring the views and experience of cancer patients and their families and carers into the cancer research community. ICPV provides researchers, clinical trials units and cancer networks with access to a trained and supported group of patient and carer advocates, thereby offering unique access to patient experience and to the committed, informed, independent and unfiltered patient voice.

"We believe that clinical research is improved by patients being partners with clinicians and healthcare professionals, rather than passive recipients of healthcare".





WELCOME FROM THE PRESIDENT, MAGGIE WILCOX

“Welcome to the very first ICPV Newsletter which has been produced just in time for me to wish you all a lovely Christmas and a happy and enjoyable 2015.

Isobel Anderson who joined us this year has kindly offered to edit a newsletter for us but will need a regular supply of material if this is to be successful. It does not have to be related to ICPV activity and it would be good to receive feedback from members’ involvement in other groups, recommendations regarding articles, events attended, opportunities for promoting ICPV etc. We hope to produce one quarterly but will start with bi-annually.

Welcome to new members of ICPV who have joined us this year – Elspeth Banks, Katrina Randle, Sam Brace-McDonnell, Stephen Thomas, Roger Wilson, Isobel Anderson, Ann Russell and Anna Wallace. Thank you to all members who have contributed to the further building of ICPV’s value in cancer research”.

- EORTC 1st Survivorship Summit, Brussels, 30-31 January 2014
- ICPV Members Day, Education Centre, Queen Elizabeth Hospital, Edgbaston, Birmingham, 4 April 2014
- Cancer Primary Care Research International Network (CA-PR1) Conference, Winnipeg, Canada, 10-13 June 2014
- NCIN Cancer Outcomes Conference, Birmingham, 9-10 June 2014
- Wales Cancer Bank 10th Anniversary Celebration, 17-18 June 2014
- ICPV Summer School, Supportive Interventions, University of Sussex, Brighton, 4-5 July 2014
- ICPV VOICE Course, Barts Cancer Institute, London, 1-5 September 2014
- ABPI Patient Forum, London, 11 September 2014
- ISOQOL welcomes the first Patient Engagement Scholars, Samantha Brace-McDonnell and Carolyn Morris. Berlin, 15-18 October 2014
- Europa Donna Symposium, Medical Society of London, 1 October 2014
- ESSO-BASO Congress, Arena and Congress Centre, Liverpool, 29-31 October 2014
- NCRI Cancer Conference, Liverpool, The Dragon’s Den: Involving Consumers in Your Research (sponsored by CRUK), 3 November 2014
- INVOLVE Conference, Birmingham, 26-27 November 2014
- Britain Against Cancer Conference, Central Hall, Westminster, 9 December 2014

ICPV members take part in Conferences by giving presentations about their experiences, engaging in debate with clinicians and researchers, and raising awareness of the work of ICPV.



REVIEW OF EVENTS

Attending and Speaking at Conferences

National Cancer Research Institute Cancer Conference, Liverpool, November 2014

The highlight of the year was the group's attendance at the NCRI Cancer Conference



Photograph on left which includes some ICPV members was taken at Reception kindly organised for lay delegates by Eileen Loucaides from NCRI

Integrating Palliative Care with Oncology Roger Wilson of ICPV opened this session. His 'patient view' was wide-ranging and supported by many references. Speakers from Italy and Finland who are actually working this way, confirmed the value. The theme of the session was summed up by the quotation: "The truth is that the principles of palliative care can be applied to many patients throughout the disease trajectory to alleviate symptom distress, provide emotional support, and facilitate communication and decision-making concurrent with cancer treatments". (Dr David Hui, MD Anderson Cancer Center).

The Cancer Drugs Fund An interestingly framed debate was held during the conference to discuss the controversial issue of whether British cancer patients have benefited from the Cancer Drugs Fund which was introduced in 2011 with £200M set aside by NHS England for the purchase of expensive cancer drugs that have either been rejected or not yet approved by NICE, the National Institute for Health and Care Excellence.

The title of the debate was 'Cancer Drugs Fund in England - Has it Been Good for the Patients?', chaired by Professor Malcolm Mason. Professor David Cameron (Scotland) and Professor Peter Clarke (England) presented evidence for its defence. Dr Tom Crosby (Wales) and Dr Martin Eatock (Northern Ireland) were against the motion.

The Yes argument, 'the fund increases patient access to rarer medications', addressed the fact that patients with conditions other than cancer don't have access to specialist drugs funds and discussed that not all the devolved nations have access to this sort of funding.

The No argument, 'reinvesting the fund would improve current treatments'. Dr Tom Crosby, Medical Director at the Velindre Cancer Centre in Cardiff, presented the case for the No Camp and suggested that: "money would be more wisely spent on establishing better systems that incorporate cancer prevention, public awareness, earlier diagnosis, improved access to treatment, and the commissioning of drugs through evaluation and research".

Some very valid points were discussed at this debate and the concluding vote from the audience was overwhelmingly against the motion.

Front line perspectives on care for women treated for breast cancer Another powerful discussion was held with Professor Alastair Thompson, Professor of Surgery, University of Texas MD Anderson Cancer Center, Honorary Professor of Surgical Oncology at University of Dundee and Visiting Professor of Surgery at Imperial College London; and Maggie Wilcox of

ICPV. This discussion was part of a parallel session on interface between hospital and primary care and their presentation looked at front line perspectives on care for women treated for breast cancer. It was enhanced by Professor Thompson's perspectives of both UK and US healthcare systems and it focussed on the surgical pathway and follow up, consequences of endocrine therapy and upper limb issues. He spoke about the use of pain relief to support early discharge from hospital, while Maggie pointed out the need for individualised decisions regarding length of stay, especially for those who live alone or conversely in busy households with young children. Options for extended endocrine therapy and effective symptom management were discussed and it was pointed out that there is less than a 50% adherence to tamoxifen for five years. Also highlighted was the fact that many women switching from tamoxifen to an aromatase inhibitor are not aware that the AI remains in the system for a far shorter time than does tamoxifen and therefore consistency of timing is necessary.

Minimising upper-limb complications was raised and Margaret Grayson pointed out the challenges that patients suffering from lymphoedema have when travelling.

The Dragon's Den Session gave researchers the opportunity to meet with patients and carers who are experienced with input into cancer research in order to receive feedback and advice. This was organised by the Consumer Liaison Group and was attended by some ICPV members whilst attending the NCRI Conference.

Overview of development of cancer services by Professor Sir Mike Richards, National Cancer Director This talk highlighted that, although survival rates are generally improving, in many tumour groups that gap is not closing. However, at least we have come out of our denial and know we need to work to close the gap. He went on to describe the period from 2000 to 2012 as an "age of enlightenment" with political will resulting from the actions of patients and charities. He highlighted the role of the registries and other data sets.

(read also Elizabeth Benms' notes from sessions she attended at NCRI Conference: <http://newnormal.blogspot.co.uk/2014/11/the-debate-ncri-cancer-conference-ii.html>)

Britain Against Cancer Conference, Westminster, 9 December 2014

Several ICPV members attended Britain Against Cancer conference in December this year. It was a great networking event and the highlight of the day was the afternoon breakout session "Whose Data is it Anyway?". The session was jointly hosted by CRUK, NCIN and ICPV and chaired by Baroness Delyth Morgan. There were 3 short talks from Emma Greenwood (CRUK), Chris Carrigan (NCIN) and Hilary Stobart (ICPV). This was followed by table top discussions on the use and collection of data. From these talks key issues were produced to be taken back to the All Party Parliamentary Group. Well done everyone.

Maggie Wilcox was disappointed that: "John Baron's guidance that this was parties working together was ignored in favour of some blatant electioneering and point-scoring".

INVOLVE National Conference, National Exhibition Centre (NEC), Birmingham, 26-27 November 2014

The INVOLVE national conference brought together people with a common interest in public involvement in the NHS, public health and social care research, and included members of the public, service users, researchers, research commissioners and representatives of voluntary sector organisations.

A presentation was made by ICPV members, Hilary Stobart and Margaret Grayson, on ICPV VOICE Science for Advocates: Quality Advocacy Needs Quality Education.

Carolyn Morris gave a presentation on Palliative Care, on behalf of CLG.

Maggie Wilcox was invited to join the panel for INVOLVE Question Time which provided lively and informative debate.

There was an excellent presentation by Tracy Browne, Director of Sense about Science. She promised to investigate concerns raised by some researchers about pressures on centres participating in Genomics England with anxieties about lack of PPI, feedback of incidental findings, and genetic counselling.

James Lind Palliative Care Priority Setting Partnership, London, November 2014

Jacqui Gath collected responses from ICPV members for a survey on palliative care prior to attending this workshop. The input from ICPV was greatly appreciated by the organisers and helped to make the day a success. The results of the workshop will be published on 15 January 2015.

European Society of Surgical Oncology/British Association of Surgical Oncology (ESSO/BASO) Conference, Liverpool, 29-31 October 2014



Lesley Turner, Maggie Wilcox and Pat Fairbrother were fortunate to obtain free registration to attend the whole of this prestigious conference. Jacqui Gath was funded by Lynda Wylde, Consultant Surgeon, President-Elect of BASO, and enthusiastic supporter of patient advocacy in cancer research - other surgeons please note!

They would like to thank Professor Riccardo Audisio, the BASO President and Congress Chair, for making this possible and for allowing ICPV to hold a video session in the Poster Area on the education and scientific mentoring for effective patient advocacy in Cancer Research. Lesley reported as follows:

“The Conference was designed to promote the highest standards of surgical care in the management of patients with solid tumours. The general theme was “Quality outcomes from a global perspective”. Doctors

attended from many countries including India, Uzbekistan, Egypt, India, Netherlands, Italy, Austria, USA, Belgium, Czech Republic, Norway, China, Poland and Japan.

A highly valued Scientific Programme, including many international speakers presenting on the very latest trends and developments within surgical oncology, was presented. For the first time, the Congress included six tracts: Breast, Colorectal, Oesophago-Gastric, HPB, Nursing and Miscellaneous (Head and Neck, sarcoma/melanoma, pelvic cancer). There were “Meet the Expert” breakfast sessions and Plenary Debate Sessions in recognition of the importance of a multidisciplinary approach to cancer patient care. There was a particularly interesting joint symposium about the expansion of the Nurse Endoscopist programme with Richard Sturgess (United Kingdom) and his team of nurses who have transformed the services offered to Patients by training up nurses to carry out colonoscopies and ERCPs.

Video sessions including cutting edge expert videos provided delegates with a unique educational opportunity. ICPV Members, Lesley Turner, Maggie Wilcox, Pat Fairbrother and Jacqui Gath, presented a session on Thursday 30 October 2014 showcasing the VOICE video and answering questions on educating and mentoring patients to become effective in cancer research. The current BASO President and Congress Chair, Professor Riccardo Audisio, and the new President elect, Ms Lynda Wyld, Senior Lecturer in Surgical Oncology from the Department of Oncology at the University of Sheffield both attended this session which we understand was the first time a session had been presented by lay advocates. Exhibitors included Genomic Health, The European Oncology Nursing Society (EONS), Merck, Sysmex and Plasma Surgical. The posters were particularly interesting and varied from “Predictors of complementary and alternative medicine use in breast cancer care: Results of multi-centre survey in Bandung, Indonesia” to “Extended rotational flap for closing defects of upper-lateral segment of the breast. The useful trick in oncological breast conserving surgery (Ukraine).”

ICPV offered an ICPV model of Dragon’s Den to two research projects, one in breast and the other in head and neck.

Maggie Wilcox feels that, in order for ICPV to attend EU conferences as UK advocates, we do need to find funding. UK advocates are very involved in effective advocacy in cancer research. We can share our experiences and promote patient advocacy in other European countries.

Spotlight on Research event, Royal Derby Hospitals, 29 November 2014



Pat Fairbrother and Hilary Stobart representing ICPV at the Spotlight on Research event, Royal Derby Hospitals

ICPV were asked to display some material at a Spotlight on Research event at the Royal Derby Hospital Medical School on Saturday 29 November 2014. Pat Fairbrother had met Dr Cristina Tufarelli, a Biologist at an event in the Research and Development department of the hospital the year before and was impressed by her enthusiasm for wanting to find a way of introducing research to the public. Thus when Cristina mentioned putting on a public event in the Medical School this autumn, Pat jumped at the chance and offered to put on a display of materials showcasing ICPV, and Hilary Stobart was delighted to accompany her at the event.

The event showcased the hospital's work with improving care in diabetes, muscular disability, safe drug use for children, POSNOC, a large breast cancer trial involving 50 hospital trusts for ten years (in which Pat is a co-applicant). Pat and Hilary took the opportunity of showing the Voice video which ran throughout the event. The day was a success and will hopefully be repeated next year.

International Society for the Quality of Life Research (ISOQOL) Conference, Berlin, 15-18 October 2014

The 21st ISOQOL conference in Berlin welcomed Samantha Brace-McDonnell and Carolyn Morris, the first Patient Engagement Scholars to attend the scientific conference and share their perspectives as patient partners. This event was organised by Cancer Research Partnership Group and attended by ICPV members who are also members of CPRG. Samantha reported on the conference as follows:

“The conference programme presented some very interesting symposia and sessions which we wished there had been more time to explore and learn from. The poster exhibition across the days of the conference provided the opportunity to engage with individual delegates and explore some of the more intricate issues around patient engagement and the accessibility of research outputs for the general public on a global level. This year demonstrated that a new model of organised and inclusive patient involvement and engagement has enhanced the experience of lay delegates. As well as the two funded patient scholars there were seven other patients and partners attending who were all contacted prior to the conference and we all got together throughout the conference, facilitated by ISOQOL members, to share our experiences with each other and ensure we were all actively involved in the conference programme.

The overarching feeling at the end of the conference is excitement for the future of patient and public engagement in research and healthcare. As the first Patient Engagement Scholars we are enthused by the ISOQOL community's response to our presence and the future involvement of patients within the scientific community. The importance of the patient agenda has been recognised as integral to the work of academics and clinicians and we look forward to taking this forward to the ISOQOL conference in Vancouver next year!”

Europa Donna Symposium, Medical Society of London, 1 October 2014

Mairead MacKenzie and Simpi Skosana attended the 20th anniversary meeting of Europa Donna. The theme was *'Breast Cancer: 20 years of Progress - What Next?'* Mairead reported on the symposium as follows:

“We had two wonderful speakers. The first was Professor John Yarnold who covered the developments in radiotherapy from the harsh treatments of the past to the newer more targeted therapies. He also clearly showed the impact on survivorship that radiotherapy provides and that future treatments will be safer and be given when and where needed.

The second speaker was Professor Ian Smith who concentrated on the developments in chemotherapy and endocrine therapy. He felt that the biggest impact in recent years was the discovery of Herceptin. It meant that women diagnosed with high grade HER+ cancer moved from a survival rate after 5 years of 25% to 75%. He felt that this discovery paved the way for the development of the targeted therapies we see now. In the future, patients will have a wide range of therapies available to target their particular variant of the disease. His hope was that this will in the future reduce the need for surgery.

All in all a very stimulating evening by two brilliant speakers.”

Association of the British Pharmaceutical Industry (ABPI) Patient Forum, 11 September 2014



Christine Allmark, Adrienne Morgan and Maggie Wilcox of ICPV have been attending this forum for some time now, and this September Mairead MacKenzie was delighted to experience this forum for the first time.

Maggie and Mairead attending the ABPI Conference where they hosted an ICPV stand in the Exhibition Area. <http://www.abpi.org.uk/>

Mairead reported as follows:

"I felt very much the new girl but there were a few familiar faces at the meeting: Jane Lyons of Cancer52, and Kate Oake who is a Patient Relationship Manager with Pfizer. Kate is especially supportive of ICPV and has been instrumental in negotiating funding for us.

The key discussion was an update on a project to develop a guide for collaboration between patient groups and industry. This would seem to be essential and hopefully help to clear up a few misconceptions and make it easier for both parties to collaborate. I will keep you informed regarding the progress of the guide which, if all goes to plan, will be available in the early part of 2015. The ABPI Patient Forum meets several times per year and we hope that an ICPV member will be in attendance at these meetings."

Wales Cancer Bank 10th Anniversary Celebrations, 18 June 2014

This event was hosted by journalist and broadcaster Nick Ross, famous for the launch of Breakfast TV. Nick is currently the Chairman of the Wales Cancer Bank Advisory Board, a position he has held since its inception in 2004. Speakers at the event included Professor Malcolm Mason, Chair of Clinical Oncology and Director of WCB, Mr Rick Greville, Director of ABPI Cymru, and Professor Peter Johnson, Chief Clinician for CRUK. Their talks highlighted how the facilities provided by WCB have facilitated research and development in both the academic and industrial setting. A question and answer session then followed.

Hilary Stobart participated in a debate about who should recruit/consent potential donors to NHS Tissue Bank. She spoke about the issue of lay recruiters and a surgeon gave his perspective. An electronic vote showed an increase of around 18% in favour of lay recruiting.

Cancer Primary Care Research International Network (CA-PRI), Winnipeg, Canada, Conference 10-13 June 2014

Derek Stewart of ICPV attended the CA-PRI Conference in June this year to promote the work of the CLG and ICPV. He said that Canada has been looking closely at how we organise research and is particularly interested in our work on public involvement. Plenary speakers at the Conference included Dr Eva Greenfield on Building Partnerships in Cancer Prevention Research, Dr Patricia Martens on Building Partnership with Decision-Makers: Lessons from the Manitoba Centre for Health Policy and the Award-Winning "The Need to Know" Team, and Dr Simon Sutcliffe on Cancer Research and Primary Care: The Global Perspective.

NCIN Cancer Outcomes Conference, Hilton Birmingham Metropole, 9-10 June 2014

This conference explored the 'power of information' both locally and nationally, and examined how UK-wide cancer registration data and other health related datasets are being exploited to reduce cancer incidence, mortality and morbidity. ICPV members were once again fortunate to receive bursaries from NCIN to attend this prestigious event. This is an important conference for patient advocates to attend and learn more about the use of their health data and to question the process of collection, storage and access. We were given the opportunity to host an ICPV stand, alongside Brainstrust and Cancer52. Maggie was pleased to be invited to co-judge the posters and present the awards together with Chris Carrigan.

European Organisation for the Research & Treatment of Cancer (EORTC) 1st Survivorship Summit, Brussels, 30-31 January 2014

Carolyn Morris who sits on the Psychosocial Oncology CSG was offered a place at this event. EORTC is an independent research organization dedicated to investigator-driven clinical trials and translational research and has not only an impressive track record in establishing 'state-of-the-art' treatments but also in ensuring that new cancer agents are developed and tested efficiently with the aim of minimizing delays between laboratory discovery and their therapeutic benefit for patients. Over the years, the EORTC has adapted its structure and expanded its premises to respond to the challenges of modern cancer clinical and translational research. In 2013 they developed a survivorship task force and in January 2014 they ran their first summit.

New Quality of Life Measures EORTC Quality of Life Group is now tackling the Need for Survivorship Questionnaire which will include cancer specific physical symptoms such as problems with swallowing, lymphoedema and generic issues such as return to work, fatigue and fear of recurrence. EORTC Survivorship Strategy will see many new cross-country trials of intervention, for example treatment of cancer patients suffering from fatigue. There is increasing evidence of work

difficulties post cancer, enormous pressures from insurance industries for data sharing, targeted therapies and secondary cancer risks Carolyn felt that these were all arguments for good patient/carer involvement in study design and in helping set priorities in this expanding field.

Danish PROFILES Registry Carolyn also highlighted the interesting accounts from the Danish PROFILES Registry (Patient Reported Outcomes Following Initial Treatment and Long Term Evaluation of Survivorship) <http://www.profilesregistry.nl/> This study enables the analysis of social inequality in outcomes, depression, and unemployment. Carolyn said that: “findings from this study have led to some unresolved issues in this field”.

Priorities in Sexuality Research, by Lesley Schover, MD Anderson Cancer Center, Houston, Texas, USA Dr Schover highlighted the unmet needs of cancer patients with regard to the physiology and psychology of sexuality and fertility. It was felt that mental health professionals should be trained in ‘cancer and sexuality’ and that health care professionals need to be comfortable discussing these issues.

Fatigue Studies, by Dr Ollie Minton, Locum Consultant and Honorary Senior Lecturer, St George’s University of London In a recent multi centre survey, fatigue has been highlighted as one of the biggest problems for patients during treatment. Dr Minton would like to add fatigue management to routine treatment monitoring and standardised across tumour types. Current evidence (mostly from breast but now from prostate patients) suggests that aerobic exercise, psychosocial and educational programmes, acupuncture, and ginseng (positive trial in high impact journal) are all effective in treating cancer patients with fatigue.

Two speakers gave a patient perspective:

Patient Perspective, by Kathy Oliver, International Brain Tumour Alliance Kathy’s list of topics for the future included the impact of diagnosis on family and friends, ramifications of recurrence, anticipatory grief, and faster and more accurate diagnosis for rarer cancers. Carolyn felt that: “Kathy gave a clear and compelling case for patients as research partners from the very beginning in evaluating proposals and design of studies, especially soft end points”.

Life Beyond Cancer, by Jane Maber, Medical Director, Macmillan Jane described this programme which was set up after recognition that two million people in the UK are living with cancer. A recovery package has been introduced for newly treated patients, which feeds back into the system via a trusted source. One of the issues was how to get cancer patients to use life style advice on diet, physical activity and weight control. It was felt that although the need for services to provide good advice is now recognised, for those who do seek out information, Internet sources are very confusing.

Overall, Carolyn felt that the EORTC Conference was very informative but lacked the same impact and collaborative approach that patient advocates have become used to in the UK.

REVIEW OF ACTIVITIES

Study Days/Courses Attended

ICPV’s fundamental aim is to improve clinical research by providing the patients’ perspective. We believe this leads to better recruitment to clinical trials and faster improvements in treatments and outcomes for all cancer patients. ICPV meets its aim by organising study days, collaborating on clinical studies, responding to consultations, and raising awareness and encouraging participation.

ICPV Members Day, Queen Elizabeth Hospital, Birmingham, 4 April 2014

ICPV held a very successful members day on Friday 4 April. Queen Elizabeth Hospital generously hosted the event and we enjoyed some excellent talks and lively debate facilitated by ICPV member Derek Stewart. The event, which was organised by ICPV member Pat Fairbrother, gave members the opportunity to engage with consultants and researchers about various research projects. Speakers included Professor Dion Morton, Consultant Colorectal Surgeon, Professor and Head of Department of Surgery, University of Birmingham; Professor Pam Kearns, Professor of Paediatric Clinical Oncology, University of Birmingham, Honorary Consultant in Paediatric Oncology; Adele Frances; Maggie Wilcox, President ICPV; and Helen Bulbeck, Director of Services, Brainstrust. Many thanks to Pat for organising this excellent event.

Miss Adele Francis, Consultant Breast Surgeon at Queen Elizabeth Hospital in Birmingham gave a talk about DCIS and her new trial looking at whether surgery can be avoided in Low Grade DCIS.

ICPV Summer School, Brighton, 4-5 July 2014

Many thanks to Professor Lesley Fallowfield for once again hosting the summer school, and to Carolyn Morris and Lesley Turner for their wonderful organisation of the event. The event was sponsored once again by SHORE-C and the programme was varied, thought provoking and offered new insights into support, treatment and survivorship. The informality of the summer school, together with the small number of participants, provided the perfect setting to encourage participation in discussions. Elspeth Banks, who was supported by ICPV and NIHR CRN to attend, reported as follows:

Patient information leaflets and other decision making tools. We've got the patient but what about public involvement, by Professor Lesley Fallowfield Professor Fallowfield's final thoughts were that cancer and its treatment has become complicated, that many words and phrases are meaningless, counter-intuitive or ambiguous and that we need to ensure patients are in receipt of appropriate, accessible information in order to make informed choices.

Clinical trial design: what's good and what's poor in supportive intervention trials, by Professor Janet Dunn Professor Dunn reminded us what a clinical trial may want to assess such as biomarkers, supportive care and treatments and she set the scene by offering some lessons from history, referring to the Gold Therapy for Tuberculosis and the natural history of disease and vaccine therapy. She then went on to define the various types and stages of clinical trials, randomisation and highlighted studies that changed clinical practice.

"Chemo-brain" - Myth or fact? Memory and attention tasks, by Dr Valerie Jenkins Elspeth Banks felt that this was a session that provided her with new insight and is an area that is most certainly worthy of further research and further discussion at the Psychosocial and Survivorship CSG.

The challenges of a trial with acupuncture - ARIX, by Dr Richard Simcock Dr Simcock discussed the complaint of xerostomia (oral dryness) due to salivary hypo function and his pilot study to test the intervention of acupuncture to alleviate this difficult symptom. The group felt that this was an interesting approach to a study and they learned a little about acupuncture along the way.

Mindfulness and the MABCAN Trial, by Rachel Ryves Rachel talked about how mindfulness-based interventions can improve symptoms of distress, menopausal symptoms and fear of recurrence.

Good Practice, by Adrienne Morgan, Carolyn Morris and Hilary Stobart of ICPV Adrienne, Carolyn and Hilary presented a trio of patient-led themes, networking, broad experiences and excellent practice. Adrienne Morgan talked about the development and formation of the NCRI CSG Breast Symptom Management Working Party in which she played a crucial part. Hilary detailed the significant involvement of the six consumer members of CTRad where support and endorsement by CTRad of radiotherapy trials is a key factor in seeking funding approval from CTAAC. Carolyn discussed a collaborative approach to follow up after cancer treatment. Their talks made the group aware of their commitment to the voice of the consumer and the obvious respect in which they are held by others.

Vision on Information Confidence and Engagement (VOICE) Course held at Barts Cancer Institute, London, 1-5 September 2014.

ICPV members are extremely grateful to Professor Louise Jones, Professor John Marshall, Dr Richard Grose and their colleagues at Barts for putting together such an excellent and informative course. The course consisted of the following lectures:

- *Basic Cancer Biology - what cancer cells do*, by Professor John Marshall
- *What happens to normal cells to make them cancerous?* by Professor John Marshall
- *Hallmarks of cancer and what cancers need to do to be successful*, by Professor John Marshall
- *The trials and tribulations (and joys) of running a cancer research laboratory* by Professor Clare Isacke
- *Cancer Biology (how cancer cells do it)* by Dr Richard Grose
- *How and why we use animals to study cancer*, by Dr Richard Grose
- *Genetic Testing, Risk Assessment and Screening*, by Professor Diana Eccles, Chair of Cancer Genetics, University of Southampton
- *Different types of cancer* by Krishna Suchak, Melissa Phillips and Dan Berney, Alastair Ironside, Louise Jones and Diana Eccles.

- *Bedside to bench, tissue and biomarkers.* Practical Session by Professor Louise Jones observing the dissection and examination of a human breast.
- *How to read scientific papers* by Professor John Marshall

Lectures were held each morning followed by afternoon laboratory sessions giving students the opportunity to carry out experiments relevant to what they had learned at the morning lectures.

The students found the course to be extremely well structured and enjoyable, which can be attributed to the hard work and excellent planning by Barts staff, Professor Louise Jones, Professor John Marshall and Dr Richard Grose. A big thank you to Bec, Mairead, Chris, Adrienne and Maggie for the facilitating, guidance and support given to the students.



More about the VOICE course can be found on the ICPV website: <http://independentcancerpatientsvoice.org.uk>

Collaboration in Clinical Studies

Most of our members are involved in the design and/or running of at least one clinical trial, usually as a member of a Trial Management Group. We work as advocates at a strategic level with clinicians and clinical researchers in order to improve clinical research and outcomes for all cancer patients. Below are some of the current trials with ICPV involvement:

POSNOC Breast Cancer Study, The Royal Derby Hospitals



Pat Fairbrother ICPV, has joined the management team on a new study being led by the Royal Derby Hospitals which could change the way women worldwide are treated for breast cancer. Mr Amit Goyal, Consultant Oncoplastic Breast Surgeon and Honorary Associate Professor at the Royal Derby Hospitals has received a £2.9 million grant for the study. The work will involve more than 50 hospitals and take more than a decade to complete. Well done Pat for being part of this fascinating trial.

Mr Goyal said “If the study can demonstrate this treatment is not necessary, then thousands of women around the world will be spared its potentially unpleasant permanent side-effects which are a constant reminder of the cancer. www.posnoc.co.uk. Read more: <http://www.derbytelegraph.co.uk/Royal-Derby-Hospital-world-leader-breast-cancer/story-23021016-detail/story.html#ixzz3M6YjPCZc>

Assessing the VALUE of Progression Free Survival (AVALPROFS) Study

Mairiad MacKenzie and Jacqui Gath of ICPV have contributed to the AVALPROFS 3 year Study and Professor Lesley Fallowfield presented a poster at the American Society for Cancer Oncology (ASCO), Boston in 2014. The study was well received at the event especially by patients.



SHORE-C
Supporting Health Outcomes Research in Cancer

Assessing the VALUE of PROgression Free Survival (AVALPROFS)

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brighton and sussex
medical school

Abstract

Background: Although attractive for methodological and practical reasons, progression free survival (PFS) is not always a surrogate for overall survival (OS). Few trials include relevant patient reported outcomes (PROs) or directly address if disease stabilisation is worth treatment side effects. Methods: A pilot study obtained feedback from patients having drugs offering only PFS or modest OS gains, about the acceptability and comprehensibility of PRO measures for use in a longitudinal study. These included validated QoL tools and 4 study specific interview schedules developed in close collaboration with Independent Cancer Patients' Voice (ICPV). Results: 11 pts with metastatic cancer participated. Only one recalled the phrase PFS used in clinical consultations. Few knew their latest scan results. Some were confused about the therapeutic aims of further treatment, 4 thought it would extend survival. All had experienced or anticipated considerable treatment related toxicity. Most were not up to date on the interview schedules, provided comprehensive feedback about these and the trade-off questions. Conclusions: PFS is confusing and questions remain about its true value. Involvement of ICPV in potentially distressing research about study design, together with inclusion of feedback from pilot patients was invaluable. The longitudinal AVALPROFS study is now recruiting.

Background

Four draft semi-structured interview schedules were developed -
A. pre-treatment
B. whilst on treatment
C. at diagnosis of disease progression
D. when treatment is halted due to unacceptable toxicity
Sections 1 & 2 of each schedule comprised questions covering personal details: demographics, age, education etc. and current understanding about therapeutic aims of treatment
Section 3 covered -
• understanding of progression free survival
• preferences for quality v quantity of life
• FACIT QoL questionnaires to be used in the longitudinal study
• perceptions about treatment related toxicity (side effects) using booklet & grades adapted from CTCAE manual [a]
• preferences for a sliding scale [b] or a response scale with predefined prompts/options [c] to determine trade-offs
• feelings about the questions used in the draft interviews - particularly content, clarity and acceptability
[a] example from booklet:
Diarrhoea Definition: Frequent & watery bowel movements

Grade 1 mild	Grade 2 moderate	Grade 3 severe
Increase of 4 or fewer loose/watery stools a day over what is usual for you	More than 4 but fewer than 7 loose/watery stools a day	7 or more loose/watery stools a day, could cause incontinence

Pilot participants

- 11/19 patients approached participated
- 4 prior to starting new treatment
- 3 on treatment
- 4 who had discontinued treatment due to toxicity



Tumour sites
■ Breast
■ Lung
■ Melanoma
■ Other

Mean age - 55 yrs (range 40-75), Sex - 6 female, 5 male
Treatment is including: erlotinib, cetuximab, vemurafenib, capecitabine, everolimus, paclitaxel, etc

AVALPROFS longitudinal study

- pilot results shared with patient advisory group
- interview schedules and study design finalised
- patient representatives attended ethics review meetings with PI
- longitudinal study recruiting in 15 UK cancer centres



Summary
• drugs that arrest the progression of cancer for a while may reduce tumour burden and symptoms of disease
• unless treatment related side-effects can also be identified and effectively controlled, these new treatments may not be valued by patients
• hypothetical studies looking at time trade-offs have been conducted in this area, but important contemporaneous research with patients during therapy has not
• ethics committees and others share concerns about upsetting patients with metastatic disease about actual therapeutic gains
• committed early involvement of patients in development of measures & study design, followed by piloting assists in the initiation of comprehensive longitudinal studies like AVALPROFS

Background

Extraordinary advances have been made in the past decade with more patients cured of cancer and/or surviving longer, but psychosocial and iatrogenic harms are created by the diagnosis, symptoms of disease and treatment side-effects. Many harms are under-recognised, under-reported & consequently undertreated. Likewise potential benefits may be underestimated as patients' treatment experiences, impact on general, social, emotional and functional well-being, are not well captured; proxy rater CTCAE assessments of toxicity (frequency & severity) differ from those of patients. Increasingly, novel drugs are approved on the basis of PFS benefit alone. Quality of life is an important consideration. The need to balance improved disease control with harms of therapy raises 2 questions - does PFS really result in discernable clinical benefit for patients and are benefits' worth adverse treatment related symptoms.

Aims

- to develop 4 study specific interview schedules
- gain feedback from patients about study design and to inform modification of interviews for use in the longitudinal study
- test 2 different methods for ascertaining trade-offs between time needed to control cancer growth and worst side-effects

Results

- patients gave constructive feedback about interview schedules & QoL questionnaires
- trade-off questions difficult for some, response scale [c] preferred
- only one recalled "Progression Free Survival" being used during consultation with doctors and 4 had no idea what phrase meant: "sounds positive, hopeful to me as it's got the word survival in it"
- all patients were warned about possible treatment side effects
- worse side effect experienced was diarrhoea

Beliefs about...	aims of new treatment	benefits of new limit are / will be
feel better	4	4
extend life	4	4
slow the cancer	8	9
shrink cancer	4	4
control symptoms	4	4
give hope	1	2
doing something	2	3
reduce anxiety	2	2

References

1. Basch E, Ila X, Heller G et al (2006) Adverse symptom event reporting by patients vs clinicians: relationships with clinical outcomes. *Journal of National Cancer Institute*, 101(23): 1624-32
2. Fallowfield L & Plescia A. (2011) The value of progression-free survival in patients with advanced-stage cancer. *Nature Reviews Clinical Oncology*, 8(1): 41-7

Acknowledgements

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The study's aim is to contribute an empirically derived patient perspective about the use of progression-free survival as an appropriate endpoint in clinical trials of cancer therapy. Progression free survival (PFS) is the length of time after cancer treatment that a patient lives with the disease without tests showing that it is worsening. Although PFS is used in clinical trials as a means of testing how well a new treatment might work, a longer PFS does not necessarily mean that overall survival is improved. So if patients derive PFS benefits but overall live no longer and they suffer unacceptable side-effects from the treatment, then this PFS may be of little value. This is an extremely important study that has generated much interest.

Responding to Consultations

President's Plea

One of our major achievements has been supplying advice, comments and criticism of papers, proposals, information sheets, etc for researchers. This is done by circulating these within our google group then collating responses to return to the researchers. This is an important and key role for ICPV and has led to very effective changes and improved likelihood of success in applications. ICPV members are often invited to join trial management groups but this earlier involvement is also very important.

However, it is increasingly evident that not enough members take an active role in responding to these calls for our online input. I do recognise that it is extra work and may not be as interesting as face to face involvement but it can be done quickly by e-mail and your views are highly valued by our research colleagues.

My New Year request is to those of you who have not been motivated to join in commenting up to now. Please - have a go during 2015!

The Voice Dec 2014 (revised)

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Members' Activities within Other Research Groups

Although ICPV is independent of established UK cancer charities, they work closely with them. Some are members and volunteers of other charities. Such involvement is important when bringing our experiences as patients and trained advocates to influence the future of cancer research and evidence based healthcare.

Elsbeth Banks is ICPV's new Scottish representative. Elspeth is involved with various research groups at the Beatson West of Scotland Cancer Centre as a Patient Advocate/Consumer Representative. She offers support to the Clinical Trials Executive Committee, The House Trials Advisory Board and the Umbrella Trials Steering Committee. The Beatson is Scotland's largest cancer centre and the second largest in the UK, and Cancer Research UK Clinical Trials Unit is based within the Beatson in Glasgow. Elspeth has retired from her post in Education and is now devoted to offering her skills and expertise, both as a senior manager and her experience as a long term patient and survivor, to supporting cancer research in a tangible form.

We will be glad to receive details of ICPV members' activities within other research groups, for future Voice Newsletters.

Creating Awareness and Fundraising

A massive thank you to everyone who has signed up to help raise funds for ICPV when they shop on-line. If you have not already done so, please give it a try at <http://www.easyfundraising.org.uk/causes/icpv/>

ICPV's President, Maggie Wilcox, would really like to hear from you if you have any ideas for fundraising, would be prepared to be involved in fundraising events, know any contacts who would be interested in sponsoring ICPV, or if you have information about grants that ICPV could apply for.

MEMBERS' RECENT PUBLICATIONS

ICPV members have been collaborators/co-authors for research projects and commented on articles in professional journals. Examples include:

Comfort Blanket or Clinical Need? The Role of Follow-up for Cancer Survivors

Gasson S, MacKenzie M, Morgan A, Morris C, Randle K, Stobart H, Turner L, Wilcox M, Members of the Independent Cancer Patients' Voice (ICPV) and the Consumer Liaison Group (CLG). ICPV's Editorial on a patients' perspective of follow-up after cancer treatment published in Clinical Oncology was a great opportunity for ICPV and was at the invitation of Charlotte Coles. Adrienne managed a survey monkey to gather opinion from ICPV members but also members from other groups, for example Consumer Liaison Group, Rare Cancer Foundation, Cancer 52, Breast Cancer Care. Mairead, Sophie and Maggie used the responses to inform the article which has received very favourable reviews. However, the rich content of these responses has shown the need for further work which is now being planned with Professor Janet Dunn's team at Warwick University.

Biobanking in the 21st Century (not yet published)

Professor Valerie Speirs at Leeds gave us another introduction to publication by asking for a few lines from lay perspective for her chapter in a new international book on Biobanking in the 21st Century. This developed into a lay chapter which is now with the editors in the USA and we will circulate publication date as soon as notified. The text includes information from ICPV members - Helen Bulbeck for Brainstrust, Hilary Stobart on Lay Recruiting in Nottingham, Mairead Mackenzie on Breast Cancer Campaign Tissue Bank, Maggie Wilcox on Confederation of Cancer Biobanks, Margaret Grayson on the education needed for effective lay involvement.

Public Guide to Tissue Donation (in progress)

ICPV worked with Dr Bridget Wilkins and her trainee pathologists from Guys & Thomas' to survey patients, members of public and professionals to assess level of knowledge and interest in donating tissue for cancer research. These young pathologists have now produced some good slides which could be used for promoting/discussing tissue donation but our idea of producing a "Public Guide to Tissue Donation" is still a work in progress.

Making patient and public involvement in cancer and palliative research a reality: academic support is vital for success

Karen Collins, Jonathan Boote, Dave Ardron, Jacqui Gath, Tracy Green, Sam Ahmedzai.

British Medical Journal 24 September 2014. BMJ Support Palliat Care doi:10.1136/bmjspcare-2014-000750
shura.shu.ac.uk/8478/1/PPI_paper_bmjspcare-2014-000750.full.pdf

Chemotherapy and Targeted Therapy for Women With Human Epidermal Growth Factor Receptor 2-Negative (or unknown) Advanced Breast Cancer: American Society of Clinical Oncology Clinical Practice Guideline.

Ann H. Partridge, R. Bryan Rumble, Lisa A. Carey, Steven E. Come, Nancy E. Davidson, Angelo Di Leo, Julie Gralow, Gabriel N. Hortobagyi, Beverly Moy, Douglas Yee, Shelley B. Brundage, Michael A. Danso, Maggie Wilcox, and Ian E. Smith
Journal of Clinical Oncology September 10, 2014 32 (26) – ASCO Special Article.

ICPV Review 2014

ICPV's latest review can be downloaded at <http://independentcancerpatientvoice.org.uk/icpv/publications/>

ICPV NEWS

Awards/Achievements

Well done Helen Bulbeck, Director of Services at Brainstrust and her colleagues for their incredible recognition for brain tumour support. The Brainstrust collaboration with Cancer Research UK and the National Cancer Registration Service was commended at the Quality in Care Award at the Britain Against Cancer Conference held in London on 9 December 2014. The judges commented: "this was patient-driven, very topical and could well be the future. The idea that patients can access their own records is important, but the initiative was also very sensitive to patient safety and took the time to educate nurses. Consequently it was able to show good indicators of success." The concept to provide an information portal, a secure website that provides patients access to their records held by the NCRS was established following a need voiced by the brain tumour patient community and has been developed in close partnership with patients and clinicians. The NCRS collects information about all cancer patients resident in England, including histopathology reports, summaries of imaging reports, data on radiotherapy and chemotherapy and Patient Administration System data. Patients can make their own notes, record the contact details of their clinical team(s) and undertake quality of life surveys.

Maggie Wilcox has been awarded a bursary to attend the EU Data Conference in Brussels in January 2015.

Maggie Wilcox has been invited to join the British Library Awards Panel judging PhD and PostDoc students' science essays that have been put forward for this award.

Recommended Reading

From guinea pigs to partners: a changing relationship with research participants

Read Jane Cope's article on how clinicians and researchers have changed their thinking about patients/participants.

<http://www.insight.mrc.ac.uk/2014/02/25/from-guinea-pigs-to-partners-a-changing-relationship-with-research-participants/www.insight.mrc.ac.uk>

CRUK and NHS England 10 Year Vision for the Future of the Radiotherapy Services in England.

https://www.cancerresearchuk.org/sites/default/files/policy_feb2014_radiotherapy_vision2014_final.pdf

Make it Clear: INVOLVE and NIHR Guidelines on Writing Plain English Summaries for Trial Applications

It is hoped that this will influence plain English writing in protocols and patient information and, ultimately, in reporting results. <http://www.invo.org.uk/meakeitclear/>

JRC Report on Survey Conducted in 2012 and 2013 for Mapping Out the Situation of Breast Cancer Services in Europe.

It provides the necessary knowledge for the development of the European Commission Initiative on Breast Cancer (ECIBC), to ensure that ECIBC pillars would take into account diversity of setting so to facilitate their implementation at national level. It covers healthcare organisation, cancer screening, breast cancer care organisation, safety and quality, accreditation and certification schemes, competence requirements for professionals. publications.jrc.ec.europa.eu/

POSTnote on Biobanks, part of the POST series on Big Data.

ICPV members contributed to the drafting of this note, which informed Parliamentarians (and others) of the issues associated with Biobanks.

<http://www.parliament.uk/briefing-papers/POST-PN-473/biobanks>

HRA Annual Review 2013-14

The Review covers key initiatives, such as work to replace the Research Governance Framework and to improve transparency in health research, on which work is continuing throughout 2014-15. www.ra.nhs.uk/research-community/during-your-research/

INVOLVE Guidelines on Budgeting for involvement: Practical advice on budgeting for actively involving the public in research studies, June 2013

These guidelines offer advice on expenses and payments for PPI/consumer involvement in trials, especially Trial Management or Steering Groups. Richard Stephens pointed out that any such funding should be included in the costs of the trial grant application. The guidelines outline how the costs might be calculated, together with some suggested amounts.

www.invo.org.uk/

Improving the Experience of Care for Cancer Patients: Using Cancer Patient Experience Survey (CPES) Data to Drive Improvements. Introductory Guide to Quality Improvements.

Published by: NHS Improving Quality in November 2015. Review date November 2015

<http://www.nhs.uk/qualityimprovement/publications/improving-the-experience-of-care-for-cancer-patients.aspx> ISBN: 978-1-910550-05-2

Low grade Ductal Carcinoma in situ (DCIS): How best to describe it? Authors: Fallowfield L, Mathews L, Francis A, Jenkis V, Rea D.

ICPV held detailed discussions about DCIS at the Brighton Summer School. This publication gives more background to these discussions.

<http://dx.doi.org/10.1016/j.breast.2014.06.013>

Writing about Biomedical and Health Research in Plain English: Guide for Authors/Access to Understanding,

Published by British Library and others, November 2014.

<http://www.access2understanding.org/guidance>

Metabolomics and Systems Biology in Human Health and Medicine. Edited by Oliver A H Jones, RMIT University, Australia (Maggie's nephew). "The metabolomics and systems biology approach to research can be applied to many disciplines. This book provides a solid introduction to medical metabolomics and systems biology, and demonstrates how they have been applied to studies in medicine and human health, including nutrition and pathogenic microorganisms. Following core themes of diagnosis, pathology and aetiology of disease, this book provides a reference for health care professionals interested in how to use metabolomics for medical research."

www.cabi.org

We hope that you enjoyed reading the first edition of The Voice Newsletter and would like to thank all those who have contributed. For the next edition scheduled for June 2015 we would welcome further input from members. Any news from members will be appreciated. We would be particularly interested to receive:

- Reviews of conferences/meetings attended
- Your involvement in Clinical Trials
- Activities within other research groups
- Members' recent publications, as author or co-author
- Your opinions about issues you feel strongly about
- Flyers for future events
- Fundraising activities
- Members personal achievements or news of interest

We thank you in advance and wish you all a Merry Christmas and all the best for 2015.

Dates for Diary

- British Thoracic Oncology Group (BTOG) Conference, Dublin, 28-30 January 2015. ICPV Members have been invited to attend this conference. Latest deadline for registration is Friday 9 January 2015 (email Dawn Mckinley on dawn.mckinley@uhl-tr.nhs.uk for details)
- European School of Oncology Breast Screening Conference, June 2015. Maggie Wilcox invited to speak on 'Patient Perspective Post Marmot Review'
- NCIN Cancer Outcomes Conference, Belfast, 9-10 June 2015 (bursaries will be available)
- NCRI Cancer Conference, Liverpool, November 2015



More detailed information about ICPV membership, activities, achievements can be found on the website www.independentcancerpatientsvoice.org.uk