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“I have worked with ICPV on the development of several clinical trials, most notably OPTIMA for which I am the chief investigator. ICPV has played an important role in ensuring the success of OPTIMA from very early on in its development through securing funding for the feasibility phase of the study, OPTIMA prelim, which successfully met its recruitment target in April 2014. Adrienne Morgan has been a member of the study development and trial management group throughout this period. Through Adrienne, we have had access to the advice and opinions of other members of ICPV. These helped shape the initial study design and led to an important modification for the proposed design of the main OPTIMA study, which is now being considered by the funder. ICPV members made important contributions to the initial patient information sheet for OPTIMA prelim and facilitated three crucial patient focus groups that resulted in important insights into the attitudes of potential participants, resulting amongst other things in changes to patient information materials. Without the involvement of ICPV, it is likely that OPTIMA would have followed a much more difficult road than has been the case.”

Professor Rob Stein

Consultant in Medical Oncology, University College London Hospitals
and Professor of Breast Oncology, UCL

Welcome

By Maggie Wilcox, President of ICPV



Maggie Wilcox
President of ICPV

Welcome to another update on Independent Cancer Patient Voice. Our growth in membership and activity continues to confirm the value of the direct and unfiltered patient involvement in cancer research and the ability of lay people to provide an informed and realistic patient perspective to trial design and development. It reinforces the urgent need for funding to provide the education and experience needed for effective patient advocacy to be maintained and developed. The need for funding needs to match the growth in membership in order to maintain the quality of our input.

ICPV started with a few people meeting in a Camden pub, sharing travel costs and discussing how we could make patient engagement in cancer research more effective – and more satisfying. We decided that our primary aim would be to find, educate, mentor and support people who, having been treated for cancer, were interested in participating in the research needed to improve outcomes for future cancer patients.

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

“ The Adele Francis Foundation is a charitable trust established to support cancer research and to foster a research ethos within the treatment of breast cancer. It was set up in Memory of Professor Adele Francis who sadly passed away in 2017. The charity is dedicated to cancer research and education. We hope to raise enough money to fund a Surgical Research Fellow to work at University Hospital Birmingham and University Birmingham to continue some of Adele’s work and to explore and develop new ideas to improve patient care.”

The Adele Francis Foundation.

Whilst ICPV now has over 60 members from across the UK, we still need to increase our membership particularly in the North and in Wales. The enthusiastic hosting of our study days by academic units helps us to improve our geographic spread and is much appreciated – as is the continued teaching, encouragement and support of our professional colleagues. Our study days have continued and, through the exceptional assistance of the scientists at The Barts Cancer Institute, we have now been able to achieve our aim of a Science for Advocates Course. VOICE is a 5 day residential educational course based on the American Project LEAD training but with the unique addition of lab based experience which is proving very effective. Warwick CTU hosted the VOICE course in 2016 and also hosted a Clinical Trials workshop for ICPV members in 2018.

We are also keen to promote the need for psychosocial research to improve the quality of life during and after treatment – especially for those for whom treatment is not successful. With the increase in long term survival there is a need to collect data and improve the quality of that survival. Sussex and Stirling Universities have both hosted psychosocial oncology workshops for ICPV.

ICPV has continued to collaborate in National and Local Cancer Research. We have had involvement with academic units, charities and other organisations and taken part in stakeholder events. These have included the following:

- All Party Parliamentary Group (APPG) on Cancer
- European Breast Cancer Standards Working Group
- Association of Breast Surgery (ABS)
- British Association of Surgical Oncologists (BASO)
- Health Research Authority (HRA)
- Human Tissue Authority (HTA)
- National Clinical Audit Breast Cancer and the Older Person
- National Institute for Health and Care Excellence (NICE)
- The Association of British Pharmaceutical Industries (ABPI)
- Royal College of Radiologists
- UK Screening Services – National Adult Reference Group
- Use My Data

Members provide an informed and independent lay perspective in many areas. We recognise the importance of encouraging active involvement from all our members in order to meet the requests for quality patient advocacy in research. We can often meet requirements through discussion on our confidential Google Group. We also need to raise funding to improve our efficiency and communication both with members and with researchers and research organisations. Most members, although interested in other health research, have limited spare time and wish to concentrate their activity to the research which will lead to more effective treatments for future cancer patients.

I am honoured to be president of an organisation which Professor Alastair Thompson recognised at a national meeting as “The patient group of choice for researchers” and whose members recognise that interest, education and a sense of humour enables us to enjoy providing an effective VOICE for patient benefit in cancer research.

More ICPV do

What we do

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 genuine patient experience and to the committed, informed, independent and unfiltered patient voice.

ICPV offers training opportunities to cancer patients to improve their clinical knowledge and research awareness and help them communicate effectively with clinicians and researchers. Experienced cancer patient advocates are encouraged to become members of ICPV.

ICPV engages with clinicians and researchers in a variety of ways including regular study days, which provide training opportunities for patients and clinicians alike. We help design clinical studies and we respond to consultations on cancer care and research, whether strategic consultations or issues around particular trials.

How we work

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

We aim to work within the National Cancer Research Institute (NCRI) Framework with proper monitoring and review of our activity, the impact we have on the research process and the value we add to research outcomes. 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.

As data and tissue use is becoming ever more important in this era of personalised medicine we are pleased to collaborate with organisations such as useMYdata, CMPath, HRA and HTA as well as being involved on an International basis.

“Increasingly regulatory bodies are demanding core support from patient advocacy groups through the research process. ICPV have been an invaluable help to our translational research program to understand cancer evolution through longitudinal cohort studies such as TRACERx. From trial concept development, through to protocol writing and regulatory submission, ICPV have provided invaluable advice at every step of the process. Their network and attention to detail is unparalleled. Their ability to canvas opinion during protocol development helps us adapt to the needs of patients rapidly, accelerating the approval process and hastening trial recruitment. I look forward to further collaborations with ICPV during the course of TRACERx and other studies we are planning. ”

Professor Charles Swanton

Royal Society Napier Chair in Oncology,
The Francis Crick Institute, London

Membership

ICPV membership has continued to grow steadily. There are currently over 60 members from all over the UK, from Southampton to Glasgow and Belfast.

All of our members are either cancer survivors, or have cared for someone with cancer. Some have had both those experiences, and several have been trial participants. We have a wealth of patient experience and a rich mix of professional expertise, with backgrounds in family, academia, business, law, local government, education, corporate communications, healthcare, arts and science. Because of the nature of our activity and the necessary level of commitment to learn as well as to participate in research, ICPV will not appeal to all cancer patients. We recognise that we are not “representative” – hence our preference for the term “Patient Advocate”.

Trustees

The brief profiles of our Trustees demonstrate the wealth of experience at the core of our organisation:



Elspeth Banks

Before she retired in 2011 Elspeth was headteacher of Strathaven Academy in South Lanarkshire, Scotland. Following a diagnosis of malignant melanoma in 1996 Elspeth had recurrences in 2002 and 2004. During this period, she had extensive surgery and participated in an EORTC clinical trial from 2002-2004.

Elspeth was a founder member of the West of Scotland Melanoma Support Group in 2003. With the group she has lobbied on various issues linked to malignant melanoma, public awareness and health education. In 2011, she was invited to join research groups at the Beatson West of Scotland Cancer Centre and since then has been an active consumer member of the Clinical Trials Executive Committee. In October 2013, she joined the NCRI Psychosocial Oncology & Survivorship Clinical Studies Group, its Lifestyle and Behaviour subgroup and the NIHR Consumer Forum.

Elspeth is increasingly involved as a co-applicant and/or a member of steering groups/trial management groups/PPI Advisory Groups in respect of a number of clinical trials and intervention studies across the broad range of tumour types and responds to many requests for guidance and advice in reviewing protocols, funding

“ There is an increasing emphasis on the benefits of gaining patient opinion and input when preparing proposals for research funding, so organisations like yours will become even more valuable, hopefully this will come with deserved recognition.”

Suzanne Johnson, Research Associate
Division of Cancer Sciences, University of Manchester.

applications and patient information. She is also active in organizing and encouraging patient and public involvement in research activities. As a member of ICPV, Elspeth is delighted to have benefited from participation in its Summer School, the excellent VOICE course offered in conjunction with Barts Cancer Institute and the many rewards of membership of this hardworking patient advocate community.



Pat Fairbrother

Diagnosed with breast cancer 1999 which resulted in a skin sparing mastectomy and reconstruction. Working in healthcare, which included a contract as patient involvement facilitator, gave her a unique insight into the need for patients to be involved at the heart of planning services. Pat developed an interest in research after working at a regional and national level with breast cancer charities, and local cancer services. She joined ICPV as a virtual member whilst living in New Zealand where she carried on with voluntary work with national cancer organisations.

Since coming back to the UK Pat has become involved in several research projects. She currently sits on the executive committee of the UKDCTN (UK Dermatology Clinical Trials Network), represents patients on the British Assoc Dermatologists BCC and SCC guidelines review, Skin CSG for the NCRI and Non Melanoma Skin Cancer sub-group and patient representative on the East Midlands Skin Expert Clinical Advisory Group, as well as same for Breast. Pat is also a member of several clinical studies management groups, both breast and skin and member of the Research & Academic Committee, Assoc Breast Surgery (ABS).

In July 2016 with the help of a local oncoplastic breast surgeon, Pat started up an online breast reconstruction support group, (BRAaS) there are currently 49 members from different locations in the UK and also includes some international members. Pat believes research needs the patients' unique perspective and is absolutely essential in order to make the research work.



Chris Finch

Chris is a carer to his wife, who has metastatic breast cancer. By training he is a chartered accountant, and for many years worked as finance director for charities, including, for nearly twenty years, the Biochemical Society. Chris has also been a trustee of charities in the health sector, including Breast Cancer Now.



Tom Haswell

Tom's background was in engineering and he worked overseas for many years. In 1993 at an employment medical in Jeddah, Saudi Arabia he was told he had lung cancer. He returned home to Glasgow, underwent further tests only to be told there was no treatment which would have any effect on his lung cancer and given a very short life expectancy. He took part in an early phase chemotherapy clinical trial followed by radiotherapy which had positive effects. This led him to believe that his experiences could help other patients and researchers and clinicians and for many years he has been involved in numerous organisations, groups and committees.

Some of his consumer/patient involvements include the NCRI CTRad, Screening, Prevention and Early Diagnosis Advisory Group (SPED), Consumer Forum, and Lung CSG. CRUKCTU (Glasgow), ECMC, PHE Lung Site Specific CRG, and involvement with NICE as a " patient expert " at Technology Appraisals. He is very much involved in cancer research and is co applicant, collaborator, advisor on several clinical trials and sits on TMGs, including the UKLung Matrix Trial and TSCs.

Tom was also a member of CRUK's NAEDI Funding Committee and Early Diagnosis Funding Application Revue Committee and is a member and trustee of the charity Independent Cancer Patients' Voice. He has also attended and been a panellist at the Precision Medicine Forum Conference and has been appointed as consumer member on NCRI's Cellular Molecular Pathology Initiative. He has also been appointed onto the British Thoracic Oncology Group, (BTOG) Steering Committee.



Mairead MacKenzie

Mairead was diagnosed with breast cancer in 2002. She had chemotherapy, followed by a mastectomy with immediate reconstruction, radiotherapy and endocrine therapy. Since her treatment Mairead has developed mild lymphoedema which is now under control and capsular contraction in her reconstruction which has resulted in the need for further surgery. This has prompted Mairead to feel strongly about the issues and potential problems patients face with the long-term effects of cancer treatment.

Mairead has been a member of ICPV since 2009 and currently sits on a number of trial management groups. She is a member of the Breast Cancer Campaign Now Tissue Bank Access Committee, steering group for the UK Therapeutic Cancer Prevention Network, sits on the Early Disease Subgroup of the Breast Clinical Studies Group, ICR CTSU PPI Group and the ICR BRC Breast Theme Group. Mairead is now retired and enjoys gardening, needlework, reading, walking and travelling and is active in her local WI.



Adrienne Morgan

Adrienne was diagnosed with breast cancer in 2005 and metastatic breast cancer in 2010. She is a PhD medical research scientist and worked for 20 years in academia and industry. Adrienne is involved with Breast Cancer Now's Cell and Tissue Bank since its inception and is a valued member of the Barts Cell Research Team. She is a lay member of several Clinical Trial Management and Working Groups and has close links with the National Cancer Research Institute (NCRI), instigating sub group on Symptom Management which she has chaired for 3 years. Adrienne is a founder member of Independent Cancer Patients' Voice (ICPV) and chair of the trustees.



Carolyn Morris

First diagnosed in 1999; now, since 2009, living with secondary breast cancer. Carolyn is a psychologist, (a practitioner, not an academic), and her involvements in cancer care & research reflect her interest in emotional and psychosocial effects of living with cancer, and what can be created to enable us, and those around us, to live better.

She has just come to the end of her membership of NCRI's Psychosocial Oncology & Survivorship clinical studies group, and continues involvement with a number of studies, as co-applicant on e.g. eRapid & LIBERATE, and on FASTForward & GUIDECARE trial management groups. The pioneering work of NCRI's sub group on symptom management is close to her heart, focussing as it does on quality of life matters which have huge impacts on patients during and after treatment.



Maggie Wilcox

Maggie trained in general nursing and midwifery before training to become a Health Visitor and, then a CNS in palliative Care. Maggie was diagnosed with breast cancer in 1997 and treated with surgery and radiotherapy. This was followed by a mastectomy a year later because of post-radiotherapy problems and she had ten years of endocrine therapy.

As a lay member of the NCRI Breast Clinical Study Group, Maggie's involvement became more specific to cancer research and the ethical use of data and tissue. Maggie was involved in the development of Breast Cancer Campaign Tissue Bank (Breast Cancer Now) and is current member of the BBMRI-ERIC (stakeholder group) and the European Initiative on Breast Cancer, the working group for the PHE screening programme and the oversight group for HRA and HTA working on consent issues to do with data and tissue.

Maggie's interests include spending time with family and friends, going to her local David Lloyd Club and travelling. Maggie volunteers at a local arts centre and is a member of Soroptimist International, the Arts Society (previously NADFAS) and a wine-tasting group.

"I have really enjoyed the opportunity of working together to provide a patient perspective and improve the understanding of the professional community in cancer research. The ICPV has been a highlight and inspiration and I feel a real privilege to have been a founding member of this dynamic group. I know that in your capable hands and with the boundless energy and devotion you all show that the group will continue to be seen as a leading force for good. I wish each of you success in all your endeavours and that health and happiness goes with you all"

Jill Bartrop
 Founder Member of ICPV

Thank You

The nature of ICPV membership means that we have to say farewell to people as Trustees or as Members through loss of life or because secondary disease creates different priorities – as does increasing age! We also lose the valuable input of those whose priorities change due to professional or family changes and sometimes members need to close the door on cancer related activities and resume “normal living”!

Linda Larter (MBE)

Linda is married with two sons. She was diagnosed with Breast Cancer in 1998 at the age of 35. Following treatment, she became a member of the UK Breast Cancer Coalition and then Breakthrough Breast Cancer following their mergers.

Linda was the Chairman of the Campaign and Advocacy Steering Committee at Breakthrough Breast Cancer at the exciting time when Herceptin was agreed for all and the two-week referral time introduced.

Linda has worked within local government for 25 years, and has a Fellowship of the Institute of Council Local Management. Linda has stepped down as an ICPV trustee, but remains a member of the group.

“ I am writing on behalf of Dr Keeley to thank you and your colleagues for the thoughtful comments we received on our application. We made several changes to the study design because of these and feel that the input you provided us with has strengthened our application. We chose to include the feedback we received from the ICPV and also from Breast Cancer Care as an upload to accompany the application to demonstrate how patients with and at risk of developing lymphoedema feel about treatment”

Katie Riches, Senior Research Nurse
Lymphoedema and Palliative Medicine, Royal Derby Hospital

New Members

ICPV is always looking for new members and welcomes interest from people who have been treated for, or affected by cancer. We are always mindful that cancer does not discriminate between people of different professional backgrounds. It is advisable for some prospective members to gain advocacy experience e.g. with a local group before considering joining ICPV. Members should also:

- Demonstrate an interest in cancer and research
- Want to help make a difference in the research community in collaboration with professional researchers
- Provide an advocate patient/carer perspective as part of a team
- Demonstrate an ability to give time to the group and its activities
- Have a willingness to attend study days and meetings and develop understanding of cancer and research
- Be able to take part in online discussion group
- Be a good listener and contribute effectively in a variety of settings
- Show enthusiasm and possibly a sense of humour
- Be able to work within own health limits
- Be able to respect others and observe confidentiality
- Share knowledge gained and endeavour to raise public awareness of value of research
- Be willing to represent ICPV on local and national groups to ensure transfer of information both ways

Full details of membership criteria and the recruitment process can be found on the ICPV website www.independentcancerpatientsvoice.org.uk

“I think this patient-led group is a great example of novel teamwork that we need to promulgate - members who deliver quickly. Fantastic stuff everyone!”

Prof Annie Young, Professor of Nursing
Division of Health Sciences, Warwick Medical School

ICPV members can expect to benefit from the following:

- **ICPV website – www.independentcancerpatientsvoice.org.uk**
This is regularly updated with two-way information, enabling members to share their experiences and supply information to clinicians
- Quality education and training opportunities together with peer support and mentoring
- The hosting of meetings between patients, clinicians and researchers
- The provision of other means of communication including a Google discussion group (this is a closed group for members only)
- Recognition from researchers who value the input of ICPV in their research projects
- Opportunities to take part in UK and International conferences – presenting as well as attending
- Facebook page for open comments and members activities
<https://www.facebook.com/Independentcancerpatientsvoice>
- New Twitter feed **@icpvtweets**

“ We greatly value the input we have received from our lay advocates (from ICPV) for our clinical surgical trials over recent months and years. We find having an opinion on the study from the point of view of the health service user provides an invaluable alternate angle on the project, and the way we portray it in the protocol and patient-facing documents. This also extends to the associated ethics and grant application forms, which definitely improve after PPI input. In addition to ensuring the language in patient-facing documents is appropriate and understandable, we are also starting to include lay members on our study management groups, in order that they are involved in all aspects of the study process, right through to results reporting and dissemination.”

Mr Thomas Pinkney, Senior Lecturer and Consultant Colorectal Surgeon
University Hospitals, Birmingham NHS Foundation Trust

Activity and Achievements

ICPV activity has grown and developed since the group was founded. Some of the Research Studies & Clinical Trials with ICPV involvement are listed below:



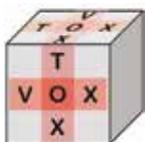
INTERLACE



Radical



Dartrix



PIONEER

RESTORE

Living with cancer-related fatigue after treatment

Biomedical Research Centre
at The Royal Marsden NHS Foundation Trust
and The Institute of Cancer Research, London



Mammo-50



REQUIRE

Supporting Practice, Work and Research of Radiotherapy Teams to Reduce Late Effects and Improve Quality of Life in Cancer Survivors

MELAMAG





Other Studies with ICPV Involvement:

ACTWELL

FoR

SCART

ANCHOR

FORECAST 2

SMART (Macmillan)

APP-AFTERC

GUIDE_care

STAMPEDE

ARISTACRAT

HeartSpare

STRATEGY

AWOS

HOLySTIC

SURECAN

CANCER AND THE POST

HORIZONS

SYSTEMS 2

GENEOMICS ERA

IMAGINT(EU)

TOMMY

COSTA-TRUC

IPET

TRACTOR

CREW

MyPEBS

Vacuum Biopsy Study

DO-IT

PROACT

Vaginal dryness/atrophy study

EPAN

PROMIS

EFFECT

RCAHT

FOCUS 4

REMoDL-B

Most ICPV involvement is as members of Trial Management Groups. For some of the trials listed, ICPV members are involved as a Co-Investigator or as a member of Trial Steering or Working Group.

ICPV also has collaboration or involvement with the following:

- ASCO Guidelines Group for Treatment of Metastatic Breast Cancer
- Association of Breast Surgeons (ABS)
- Association of British Pharmaceutical Industries (ABPI) Patient Forum
- Beatson West of Scotland Cancer Centre
- BrainsTrust
- Breast Cancer Now Tissue Bank (BCNTB)
- Cancer 52
- Christie NHS Foundation Trust, Manchester
- Cambridge Breast Cancer Research Unit (CBCRU)
- CRUK Clinical Trials Awards and Advisory Committee (CTAAC)
- CRUK Grand Challenge Initiative
- Electronic Transmission Prescriptions Programme
- European Researchers and European Joint Research Centre
- Glasgow Bio-repository and Beatson Cancer Centre CTU and Institute
- Health Research Authority (HRA)
- Health Technology Assessment panels
- Human Tissue Authority (HTA)
- Institute of Cancer Research (ICR), London
- Kidney Cancer Support Network (KCSN)
- Manchester Breast Research Centre
- Marmot Panel on breast screening)
- Medical Research Council (MRC)
- MD Anderson, Texas, link with Patient Advocates Research Network
- National Cancer Research Institute (NCRI): Members sit on site specific Clinical Study Groups and subgroups and the Consumer Forum
- National Collaborating Centre for Cancer (Wales)
- NICE Diagnostics Assessment Committee for Skin
- NIHR Cancer & Nutrition Infrastructure Collaboration
- Northern Ireland Cancer Trials Exec, Network Steering Group and Cancer Registry
- Regional Ethics Committees (REC)
- Research for Patient Benefit (RfPB): Regional committees
- Sloane Project
- Symposium Mammographicum
- Stakeholder status with National Institute for Clinical Excellence (NICE) and the All Party Parliamentary Group (APPG) on Cancer
- Surrey Cancer Research Institute (SCRI) – launched July 2014
- UK Therapeutic Cancer Prevention Network (UKTCPN)
- UKCRC Tissue Directory and Coordination Centre
- UseMyData
- Warwick Clinical Trials Unit
- West Midlands Collaborative of Surgeons (Mammary Fold and others)
- Working group for new screening info – bowel, breast and cervical cancer

“ As an oncologist conducting trials looking for new and better ways to look after women with breast cancer the support of ICPV has been invaluable. The knowledge, interest and support of the group has enabled myself and many colleagues to conduct trials which are not only scientifically robust, but also sensitive to the needs and wishes of women with breast cancer.”

Dr Alistair Ring, Consultant Medical Oncologist
Royal Marsden Hospital, London

The Rarer Cancer Foundation (RCF) has sadly folded due to the death of Andrew Wilson. Andrew was the driving force in the campaign to get full and fair access to cancer drugs and the Cancer Drugs Fund is his memorial. No-one can dispute the Fund has changed thousands of lives and improved cancer patient survival over many years.



ICPV has supported the PEACE (Posthumous Evaluation of Advanced Cancer Environment) since its inception and at the 2018 RCNi awards the research nurses team led by Foteini Rozakeas won the Excellence in Cancer Research Award. A great achievement and one we hope will further the importance of tissue donation. Maggie Wilcox and Mairead MacKenzie joined the team for the celebrations.
<http://www.ctc.ucl.ac.uk/TrialDetails.aspx?Trial=134&TherA=6>

Training

ICPV is passionate about education and development for its members and organises regular educational events. Over the past few years these have included one day workshops as well as several longer events at locations including Birmingham, Brighton, Cardiff, Glasgow, Leeds, London and Warwick.



Vision On Information, Confidence & Engagement

In 2013 ICPV achieved one of its primary goals – a week's intensive biology education for its members. This had been a goal since ICPV was founded because several members had benefited previously from Project Lead training provided in America. Through the hard work, expertise and enthusiasm of the scientists at Barts Cancer Institute we were able to hold our pilot 'science for advocates' course – VOICE – 'Vision on Information, Confidence and Engagement' in 2013. With the laboratory-based content this course is unique and especially valuable for patient advocates in cancer research. 'A study week taking patient advocates from bedside to bench' – leading to translational patients!

"The session where we discussed how chemotherapy agents work in relation to the cell cycle was the best teaching experience I think I've had – moving, informative and productive."

Dr Richard Grose
Barts Cancer Institute

The 2018 VOICE course will be once again be hosted by Barts Cancer Institute in London.

“ICPV work closely with Professor Janet Dunn and her team at the Warwick Clinical Trials Unit, University of Warwick, on early breast cancer clinical trials and have been influential in helping with the design, information, consent, trial management and trial processes for the PERSEPHONE (Herceptin duration), OPTIMA (optimal personalised medicine) and MAMMO-50 (mammographic surveillance in patients diagnosed aged 50 years or older) clinical trials. Each trial is funded by the department of health through the health technology assessment (HTA) funding stream and seeks to determine the best treatment for these populations of early breast cancer patients. The OPTIMA and MAMMO-50 trials included some early PPI focus groups to determine the experiences and views of the trial design, information and trial question for which ICPV helped facilitate. Engagement of patients early in the trial design has helped with fine-tuning these important questions and has allowed the trial team to incorporate patients’ view throughout the trial process.

Janet continues to support ICPV with her clinical trial workshops in the ICPV training days where the various trial questions and subsequent designs are discussed. One workshop concentrated on follow-up which remains an important question throughout cancer trials but still needs guidelines to address optimal care. Professor Dunn quotes “The partnership with ICPV at the formulation of the trial question and subsequent trial design has significantly improved acceptability of the trial to both patients and clinicians.”



Prof Janet Dunn

Professor of Clinical Trials and Head of Cancer Trials,
Deputy Director, Warwick Medical School Clinical Trials Unit



VOICE – Warwick, September 2016:

After three years at Barts the 2016 VOICE Course was hosted by Warwick Clinical Trials Unit from the 19 - 23 September 2016. The course covered an introduction to basic cancer biology with sessions on what cancer is, how it is caused, how it develops and how it is detected and treated. Course participants spent time in the research laboratories to help them to build their understanding.

Other topics covered were epidemiology, statistics and reading scientific papers with sessions on understanding statistics, understanding risk, epidemiology and how to read and interpret scientific papers.

For a flavour of the course please check our website for a short video and a course blog from one of the students: www.independentcancerpatientsvoice.org.uk/voice-science-for-patient-advocates/voice-2016/

Cambridge, June 2016:

ICPV members attended a two-day visit to Cambridge in June 2016 with an opportunity to see the Sanger Institute on day 1 followed by Addenbrooke's Hospital on day 2.

The programme at the Sanger Institute included a tour of the Sanger Institute and workshops that brought everyone up to date with genomic research. The following day at Addenbrookes offered tours of various departments at Addenbrookes with accompanying overviews of Brain Cancer Research, Phase 1 Trials and Breast Cancer Clinical and Translational Research activity.



Summer School, Stirling, June 2017:

A two-day Summer School with a focus on Survivorship was held in Stirling in June 2017. This was a collaboration between ICPV and the University of Stirling, organised by Elspeth Banks (ICPV) and Professor Mary Wells (NMAPH-RU Research Unit, University of Stirling).

The days were packed with discussion and debate covering survivorship terminology, patient reported outcomes, palliative care, diet and exercise and ended with a speedy run through of oncology research and the major changes that have taken place over the last 50 years.

Warwick Clinical Trials, April 2018:

12 members of ICPV attended a residential Clinical Trials Course at the University of Warwick from 17th to 19th April 2018.

The course was run by Professor Janet Dunn with organisation help from Lesley Turner and Sophie Gasson from ICPV and covered the different types of studies undertaken; consent; trial design; statistics and bringing a drug to market.

One of the highlights of the course was a visit to the West Midlands Surgical Training Centre where delegates had the privilege of seeing real body parts and having basic anatomy explained to them by the team.

For a flavour of the course please check our website blog from one of the students:
www.independentcancerpatientsvoice.org.uk/study-days/warwick-april-2018/



It comes up in support groups all the time; what happens to your tissue? Now I can talk about it with authority and encourage more people to get involved in research.



It gives me more confidence to interact with the scientific community

ICPV continues to be grateful to academic centres and researchers around the UK who have hosted the group with enthusiasm and looks forward to continuing to expand this collaboration.

ICPV plans to repeat the VOICE course and we are receiving expressions of interest from researchers keen to support this project.

“I have worked with several members of the Independent Cancer Patients Voice on a range of issues related to prevention and treatment of breast cancer. I have found them very knowledgeable and helpful to us in planning and conducting our clinical trials. It is very important to have views from patients on a range of questions related to this work. I have found that they are extremely helpful and give us advice that is based on personal experience and highly relevant to the needs of patients in our trials. I look forward to continuing to work with them on new projects.”

Jack Cuzick, Director
Wolfson Institute of Preventive Medicine, Queen Mary University of London



“ The involvement of lay people in collections of tissue samples for research has been critical in many ways but particularly in allowing professionals to feel confident about what can reasonably be asked of patients in their research partnership with them. Lay advice has been and remains very important to us in our trials of presurgical treatments of primary breast cancer; without this it is highly unlikely that these trials could have been successful.”

Professor Mitch Dowsett, PhD, FMedSci, Professor of Biochemical Endocrinology, Professor of Translational Research at Breast Cancer Now Research Centre, Head of the Ralph Lauren Centre for Breast Cancer Research, Royal Marsden Hospital

“ We know cancer patients can make an important contribution to developing and delivering clinical research if they are given the opportunity to do so. ICPV plays a valuable role in this area, in particular by equipping patients with the skills and knowledge to work effectively alongside clinicians and academics. As CRUK implements its patient engagement strategy ICPV provides us with an excellent role model in this area of work.”

Sarah Woolnough, Executive Director of Policy & Information, Cancer Research UK

Conferences/events/posters

ICPV members regularly attend major conferences and meetings, both as delegates and speakers and frequently display posters detailing ICPV activity. Over the last few years these have included:

- Annual Research Conference at the Christie Hospital
- Association of Breast Surgery (ABS)
- BBMRI-ERIC Stakeholder Group, Brussels
- Breast Annual Trials Day London
- Breast Radiology Forum Annual Scientific Meeting
- Britain Against Cancer – Westminster
- British Association of Surgical Oncology (BASO)
- Cambridge Breast Radiology
- CRUK Big Data Conference – Francis Crick Institute
- CRUK PPI and Grand Challenge
- Europa Donna Annual Symposium
- HRA PPI Steering Group and Stakeholder Meetings London, Leeds and Manchester
- HTA AGM & Public Meeting
- HTA Stakeholder Meetings
- NCRI Annual Trials Day London
- NCRI Annual Conference
- Public Health England National Screening Programmes
- San Antonia Breast Cancer Symposium (SABCS)
- UK Interdisciplinary Breast Cancer Symposium

Publications

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

1809 Results of the OPTIMA (Optimal Personalized Treatment of early breast cancer using Multi-parameter Analysis) prelim study

Stein RC, et al (inc **Morgan A**): European Journal of Cancer, 2015, 51, (Supp 3), S268
DOI:10.1016/S0959-8049(16)30762-6

Clinical Review of New Drug-Radiotherapy Combinations: Consensus Statement

Sharma RA et al (inc **Haswell T**): Nature Reviews Clinical Oncology, 2016, 13, 627–642

Co-enrolment of Participants into Multiple Cancer Trials: Benefits and Challenges.

Cafferty FH, Coyle C, Rowley S, Berkman L, **Mackenzie M**, Langley RE:
Clinical Oncology, 2017, DOI: <http://dx.doi.org/10.1016/j.clon.2017.02.014>

Comparison of multiparameter tests in the UK OPTIMA-Prelim trial

Bartlett JMS, et al (inc **Morgan A**): Cancer Research, 2015, 75, 9 Supplement, P4-11-07-P4-11-07, DOI:10.1158/1538-7445.SABCS14-P4-11-07

Defining a standard set of patient-centred outcomes for lung cancer: International Consortium for Health Outcomes Measurements-International Standard Set for Lung Cancer

Mak KS, et al (inc. **Haswell T**): European Respiratory Journal, 2016, 48, 852-860; DOI: 10.1183/13993003.02049-2015.

Development and Evaluation of a New Technological Way of Engaging Patients & Enhancing Understanding of Drug Tolerability in Early Clinical Development: PROACT

Hughes A, Landers D, Arkenau HT, Shah S, **Stephens R**, Mahal A, Simmons M, Lemech C, Royle J:
Advanced Therapy, 2016,33, (6), 1012-24. doi: 10.1007/s12325-016-0335-4

Emerging Guidelines for Patient Engagement in Research.

Kirwan JR, de Wit M, Frank L, Haywood KL, Salek S, **Brace-McDonnell SJ**, Lyddiatt A, Barbic SP, Alonso J, Guillemin F, Bartlett SJ: Value in Health, 2017, 20, (3), 481–486

“ Working alongside members of ICPV on trial steering committees has been a major step forward in breast cancer research. Having informed patient participation at each stage of the process from design to recruitment not only speeds up the process of turning a trial idea into a workable design but also brings a welcome new perspective to the whole procedure. ICPV members play a crucial role in ensuring the correct questions are asked and that they are answered in an appropriate and acceptable way.”

The late Professor Adele Francis,

Consultant Breast Surgeon University Hospital, Birmingham

Establishing priorities for UK cancer nursing research: Nurse and patient collaboration in a UK Oncology Nursing Society Delphi survey

Cox A, Arber A, Gallagher A, **MacKenzie M**, Ream E:

Oncol Nurs Forum, 2017;44, (2),192-203. doi: 10.1188/17.ONF.192-203

Establishing the Values for Patient Engagement (PE) in Health-Related Quality of Life (HRQoL) Research: an international, multiple-stakeholder perspective.

Haywood KL, Lydiatt A, **Brace-McDonnell SJ**, Salek S, (2016):

Quality of Life Research, 2017, 26,1393–1404

The European Cancer Patient’s Bill of Rights, update and implementation 2016.

Lawler M, Banks I, Law K, et al (61 authors inc **Wilson R**):

ESMO Open, 2016, 1(6), e000127. <https://doi.org/10.1136/esmooopen-2016-000127>

Exploring adherence to adjuvant endocrine therapy (AET) following treatment for breast cancer

Brett J, et al (inc **Morgan A, Morris C**): Psycho-Oncology, 2016, 3, 25.

Experience of living with cancer and comorbid illness: protocol for a qualitative systematic review

Cavers D, Cunningham-Burley S, Watson E, **Banks E**, Campbell C

BMJ Open 2017;7:e013383. doi: 10.1136/bmjopen-2016-013383

Factors associated with intentional and unintentional non-adherence to adjuvant endocrine therapy following breast cancer.

Brett J, Fenlon D, Boulton M, Hulbert-Williams NJ, Walter FM, Donnelly P, Lavery B, **Morgan A**, Morris C, Watson E:
European Journal of Cancer Care, 2016, 11, DOI:10.1111/ecc.12601

High hospital research participation and improved colorectal cancer survival outcomes: a population-based study.

Downing A, Morris EJ, Corrigan N, Sebag-Montefiore D, Finan PJ, Thomas JD, Chapman M, Hamilton R, Campbell H, Cameron D, **Stephens R** et al
Gut, 2017, 66, (1), 89-96

Identifying research priorities in anaesthesia and perioperative care: final report of the joint National Institute of Academic Anaesthesia/James Lind Alliance Research Priority Setting Partnership.

Boney O, et al inc **Gath J**: BMJ Open 2015;5:e010006. doi: 10.1136/bmjopen-2015-010006

The Importance of Quality Patient Advocacy to Biobanks: A Lay Perspective from Independent Cancer Patients Voice (ICPV), Based in the United Kingdom.

Wilcox M, Grayson M, **MacKenzie M**, **Stobart H**, Bulbeck B, Flavel R:
in Biobanking in the 21st Century, edited by Feridoun Karimi-Busheri, Springer, 2015
Adv Exp Med Biol. 2015,864, 171-83. doi: 10.1007/978-3-319-20579-3_14.

The Informatics Challenges Facing Biobanks: A Perspective from a United Kingdom Biobanking Network.

Quinlan PR, Groves M, Jordan LB., **Stobart H**, Purdie CA, Thompson AM:
Biopreservation and Biobanking, 2015, 13, (5), 363-370. doi:10.1089/bio.2014.0099

Following ICPV input into a research proposal by Jamilla Hussain, including presentation of the proposal at the Consumer Liaison Group's Dragon's Den session at the 2012 NCRI Cancer Conference, Jamilla was recommended for PhD funding by the NIHR. Professor Miriam J Johnson wrote to ICPV:

" thank you again for your great input with her application - I think she had the best PPI input I have ever seen on an application"

Miriam Johnson

Professor of Palliative Medicine, Hull York Medical School

“It has never been more important to engage patients in the development of new cancer treatments. As we move into the stratified medicine era, the complexity of treatment options will increase and we must ensure that the questions (and answers) remain relevant to the patients we are treating.

Professor Dion Morton

Colorectal Surgery Consultant, Birmingham

The Information and decision support needs of older women (>75 yrs) facing treatment choices for breast cancer: A qualitative study.

Burton M, Collins KA, Lifford KJ, Brain K, Wyld L, Caldon L, **Gath J**, Revell D, Reed MW: Psychooncology, 2015;24(8), 878-84 <http://shura.shu.ac.uk/10929/>

A little more conversation please? Qualitative study of researchers' and patients' interview accounts of training for patient and public involvement in clinical trials

Dudley L, Gamble C, Allam A, Bell P, Buck D, Goodare H, Hanley B, Preston J, **Walker A**, Williamson P, Young B: Biopreservation and Biobanking, 2015, 13, (5), 363-370. doi:10.1089/bio.2014.0099

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

Collins K, Boote J, Ardron D, **Gath J**, Green T, Ahmedzai S: BMJ Supportive & Palliative Care 2015;5:203-206

Management of hot flushes in UK breast cancer patients: comparing the clinician and patient perspective.

Fenlon D et al (inc **Morgan A, Morris C, Turner L**): Maturitas, 2015, 81(1),138, DOI:10.1016/j.maturitas.2015.02.120

Models and impact of patient and public involvement in studies carried out by the Medical Research Council Clinical Trials Unit at University College London: findings from ten case studies

South A, et al (inc **Stephens R**): Trials, 2016, 17, 376 DOI 10.1186/s13063-016-1488-9

“ I have found the input from ICPV invaluable. For example, really pertinent comments from its members have shaped the design of new clinical trials and tailored Patient Reported Outcome Measures (PROMS) to reflect what is really important for patients. In addition, the Radiotherapy for lay people conference day was thoroughly enjoyable and enlightening: I think I learnt more from the audience than they did from me!”

Dr Charlotte Coles

Consultant Clinical Oncologist, Addenbrooks,
Cambridge University Hospitals NHS Foundation Trust

Observational study of the development and evaluation of a fertility preservation patient decision aid for teenage and adult women diagnosed with cancer: The Cancer, Fertility and Me research protocol.

Jones GL, Hughes J, Mahmoodi N, Greenfield D, Brauten-Smith G, Skull J, **Gath J**, Yeomanson D, Baskind E, Snowden J, Jacques RM, Velikova G, Collins K, Stark, D, Phillips, R, Lane S, Bekker HL (On behalf of the Cancer, Fertility and Me study group): BMJ Open 2017;7:e013219. doi: 10.1136/bmjopen-2016-013219

One Small Step... An Editorial Introduction to the World's First Journal for Patient Involvement

Stephens R, Staniszewska S:

Journal of Research Involvement and Engagement, 2015, 1, 1

<http://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-015-0005-8>

OPTIMA (Optimal Personalised Treatment of early breast cancer using Multi-parameter Analysis): A prospective trial to validate the predictive utility and cost-effectiveness of gene expression test-directed chemotherapy decisions

Francis A, et al (inc **Morgan A**). European Journal of Surgical Oncology, 2016, 42, (5), S9–S10 DOI:10.1016/j.ejso.2016.02.048

OPTIMA: a prospective randomised trial to validate the predictive utility and cost-effectiveness of gene expression test-directed chemotherapy decisions.

Stein R, et al (inc **Morgan A**): European Journal of Surgical Oncology, 2016, 42, (11), S229 DOI:10.1016/j.ejso.2016.07.057

OPTIMA prelim: A randomised feasibility study of personalised care in the treatment of women with early breast cancer

Stein RC, et al (inc **Morgan A**): Health technology assessment, 2016, 20,(10), xxiii-xxix DOI:10.3310/hta20100

Sarcoma care pathways – the patient viewpoint.

Wilson R, Wartenberg M, Lecoite E, Sarcoma Patients Euronet: European Cancer Congress (ECCO), 2017, Abstract ref, 4BA (Best Abstract)

Sarcoma Patient Pathway Analysis and Recommendations For Service Development.

Wilson R, Wartenberg M, Lecoite-Artzner E: Sarcoma Patients Euronet, 2017 <http://www.sarcoma-patients.eu/en/sarcoma-reports2/policy-checklist>

See website for full details

<http://www.independentcancerpatientsvoice.org.uk/icpv-publications/members-publications/>

“ A continuing involvement with ICPV has had a huge impact on how I work, since I now ‘hear’ - or at least listen for -the patient voice in many situations I encounter, and I realise we, as medical professionals, can actually ask for input. As I am starting to consider ways of addressing research into secondary breast cancer, it gives me confidence to know that I can seek candid opinions and invaluable advice from ICPV. I don’t think it is possible to move forward without this partnership, and for that ICPV is to be applauded”

Louise J Jones, Professor of Breast Pathology
Centre for Tumour Biology and Barts Cancer Institute - a Cancer Research UK Centre of Excellence

Looking to the Future

Working with Young Researchers

ICPV's primary purpose will continue to be to work with our professional colleagues in cancer research to produce more effective treatments for future patients. ICPV has been developing links with young researchers to encourage collaboration with patient advocates early in their careers.

An example is the annual attendance and input at the annual research day held by the Manchester Breast Research Unit.

“The contribution by Independent Cancer Patients’ Voice to the large UK multicentre POSNOC trial has been vital in improving the study design, making sure outcomes important to patients are measured, and making all the study practicalities much clearer. I feel confident that we are asking the right question to improve the health and quality of life of breast cancer patients. ICPV involvement has ensured that the trial information in the patient information leaflet and DVD is easily understood, clear and presented in an unbiased manner. I am glad that their members are part of the POSNOC Trial Management Group and Trial Steering Committee and shall provide a patient and wider public perspective throughout the duration of the trial.”

Amit Goyal

MS, MD, FRCS, Consultant Oncoplastic Breast Surgeon, Honorary Associate Professor, Royal Derby Hospital

The following example from Dr Jamal-Hanjani demonstrates the appreciation of lay input by young researchers:



Dr Mariam Jamal-Hanjani

The PEACE (Posthumous tissuE donAtion in CancEr) study is a multi-centre prospective observational study intended to facilitate tissue donation, in metastatic cancer, from multiple tumour sites in the post-mortem setting. It aims to establish a model for tumour progression, and therefore the metastatic process, and to determine whether there is a relationship between intratumour heterogeneity and clinical outcome, including response to treatment and survival. Results from the PEACE study may have significant implications for personalised treatment approach in cancer, including the identification of prognostic and predictive biomarkers, therapeutic strategy and drug resistance. The PEACE study also aims to encourage collaboration with other research teams for whom access to post-mortem tissue has the potential to further guide their work in cancer research. Ultimately, through the integration of genomic and clinical data, the study aims to identify critical tumour subgroups that may preferentially benefit from specific clinical therapeutics.

ICPV have been involved in the conceptual and practical development of the PEACE study from the outset. Their experience and input has been invaluable in the protocol and patient document development, which was written in consultation with ICPV, as well as medical, palliative care and pathology experts. Their continued support has encouraged us to move forward with this study so that patients are given the opportunity to donate tissue and be involved in cancer research.

Dr Mariam Jamal-Hanjani

Clinical Research Fellow to Professor Charles Swanton
Translational Cancer Therapeutics Laboratory
UCL Cancer Institute

International Collaborations

ICPV recognises the need for collaboration with patient advocates as well as scientists in other countries but it has proved difficult to access patient advocates who are actively and effectively involved in cancer research rather than campaigning for better services and access to treatment. We are currently working to build links with international researchers and scientists with a genuine interest in effective lay involvement.

Members have attended and presented at those EU organised conferences which provided bursaries but, with a very limited budget, ICPV cannot fund all registration fees or travel costs. Examples include lung, brain, kidney, skin and breast international events. ICPV is a signatory to the Statement issued by the Wellcome Trust about proposed changes to the European Directive on Data Protection and will continue to collaborate in work on this issue. We also collaborate with Komen Foundation, ASCO, and National Breast Cancer Coalition(NBCC).

In many European countries, most advocacy appears to be limited to cancer service development, fund raising and campaigning for improved cancer treatments. ICPV's view is that there must be many European patients who, like us, would welcome active involvement in Cancer Research. This is being confirmed by enquiries from such people – some of whom have been referred to our website by their clinicians.

We have long term links with the National Breast Cancer Coalition (NBCC) in the USA who provided excellent education for several founding members of ICPV and continue to show interest and encouragement. Professor Alastair Thompson is an outstanding enthusiast of effective lay involvement in cancer research and, now working at M D Anderson in Texas, is helping establish a link with other American patient advocates whilst Esme Radin and Elizabeth Bennis are on the Trial Management Group of a European Breast Screening Trial, MyPEBS, being run from Paris. We recognise the need to expand this collaboration to other tumour groups. ICPV plans to continue its efforts to find and collaborate with research active advocates in other countries and looks forward to the support of health professionals, both at home and abroad.

At the suggestion of Professor Val Speirs, ICPV was invited to contribute a lay chapter for a new international book on biobanking. Biobanking in the 21st Century, Editors: Karimi-Busheri, Feridoun (Ed.)

Professor Alistair Thompson writes:

“The Independent Cancer Patients Voice continues to contribute very effectively and helpfully to the development of clinical trials and studies, including providing pivotal input where the “patients voice” has supported trials at key moments. ICPV members also ensure that clinicians get real world views that have in the last year or so stimulated the clinical community to reconsider the importance of symptoms in survivors through to supporting cutting edge research through tissue banking initiatives. We are fortunate indeed to have ICPV playing an active role in the development of improved treatments for cancer based on hard won evidence.”

Professor Alastair Thompson, Professor of Surgery
MD Anderson Cancer Center, Houston Texas and
FORMER Chair NCRI Breast CCSG

Membership

Reviewing our activity and membership is on the agenda at all Trustee meetings to ensure that we grow and develop in a sustainable way to maintain ICPV quality within available funding.

One of our aims must be to improve organisational efficiency. Although the ad hoc funded facilitator continues to be an enormous help, the Trustees recognise that ICPV must have a much more structured organisation which requires funding. ICPV has now gained a reputation for providing direct access to a patient perspective which is realistic, constructively critical and highly valued by researchers across the UK. ICPV recognises the need to protect its ethos whilst continuing to grow and develop.



ICPV aspirations:

- to protect our independence
- to increase membership - numbers and diversity
- to expand geographically becoming less London based
- to recruit more members with less common cancers
- to grow slowly in order to continue to provide the opportunities for education, mentoring and support to all members
- for more effective involvement from all members
- maintain trust and support of our professional colleagues
- to develop international links
- to continue to collaborate with relevant organisations
- to raise the money to fund all of the above
- Fund the appointment of a chief executive and secretarial support

What are the main challenges we face?

As we grow, we will face many challenges not least in supporting a growing number of members whilst maintaining the integrity of the ICPV 'brand'. Raising our profile amongst the research community and encompassing other types of cancer within our work are two big challenges. Funding is likely to be an ongoing challenge. We can face criticism that we are not truly "representative" or an open membership group because we are convinced that our aims require a high level of commitment to ensure the development of effective advocacy which meets the needs of both patients and researchers. Potential members are welcome to attend one of our events before applying for membership and they will be given information about criteria for membership of ICPV.

With the increase in requests for ICPV input from our professional colleagues we face a continual challenge of meeting deadlines for responses and urgently need more facilitator time.

ICPV members also need to make time for some 'normal' activities!

Finances

Our funds are used, in the main, for education for members, including study days and the VOICE course, and attending conferences and meetings. We have been fortunate in that so far all our speakers and meeting organisers have donated their time and the costs incurred were put to ensuring volunteers are able to attend.

Our income since we began has come from a variety of sources, including pharmaceutical companies (35%), members' fundraising (13%), health charities (20%) academia (19%), and fees charged (7%). We are aware that we need to remain independent of pharmaceutical companies. However, it is in the interest of all cancer patients that effective drugs are developed, and we feel that donations from pharmaceutical companies are therefore appropriate.

We believe that it is important for researchers to budget for lay input to new trials when making funding applications and we aim to recoup some of our costs in this way; this is needed to enable the participation of some members.

Members and trustees receive no payment from ICPV, except travel expenses and generously donate their time and expertise.

For more detailed information on our accounts please contact the Treasurer (details on our website).

“The importance of truly independent patients’ voices in clinical cancer research is being increasingly recognised. The NCRI and NIHR Cancer research networks, as well as those in Scotland and Wales, have pioneered public engagement in the process of clinical research in cancer, such that the UK is arguably ahead of the rest of the world in this area. However, independence of the patient voices remain as important as independence of thought and freedom from conflicts of interest amongst researchers: and the work done by this small charity is leading the way in this area. There is, in my view, a difference between advocacy and representing patients’ views and experiences, in that the former is often associated with a strength of particular views rather than the breadth of experience, and this charity has worked hard to deliver the latter.

I have worked alongside several of these individuals in the development of a number of breast cancer trials where their input has been significant: they are not ‘token patient representatives’ but active participants in the design of the studies. In addition, I have sat on committees alongside many of the seven founding individuals, and I can personally vouch for their commitment, neutrality and vision.”

David Cameron

Professor of Oncology

Edinburgh Cancer Research UK Centre, University of Edinburgh.

Acknowledgements

ICPV is grateful to everyone who has supported the group in any way since it was founded in 2009. The many examples of feedback and valediction scattered throughout this year book are illustrative of the many working relationships ICPV has established with researchers both in the UK and internationally.

A special mention has to be made to Professor Adele Francis who sadly passed away in Jan 2017. Adele was a champion of PPI and her support has been instrumental in ICPV being what it is today.

A foundation has been set up in her memory. The foundation hopes to raise enough money to fund a Surgical Research Fellow to work at University Hospital Birmingham to continue some of Adele's work and to explore and develop new ideas to improve patient care.

More information and how to support this can be found at **www.justgiving.com/fundraising/adelefrancisfoundation**

More detailed information about ICPV, activity, achievements and the future can be found on the website **www.independentcancerpatientsvoice.org.uk**

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