independent cancer patients' voice

Yearbook 1:

Opening The Conversation

A Record of Achievement 2009-2011

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Welcome

Richard Stephens
New ICPV member.

After 10 years as a cancer patient involved in research, I was asked to speak at the annual conference of the International Society for Quality of Life Research in October 2010. The invitation came as a result of my often-voiced view that cancer research for patient benefit needs to look not only at clinical outcomes, but also at our feelings and daily lives and how we cope (or not) with our cancers and our treatments.

The topic for my conference contribution was how to convince clinicians to change their practices as a result of QoL Research, i.e. research into the sort of patient-recorded outcomes that I had been advocating.

It was no surprise that the Quality of Life researchers in the audience supported my views, but it was clear that they were not satisfied with my glib approach of "listen to the patient voice and tell the clinicians to do the same."

One loaded question from a frustrated researcher summarised the problem - "Where can we find independent patients who understand research and who understand how to help us improve services because evidence shows we can and we should? Those are the kind of people who might really get things changed."

My answer was at least honest - "I don't know, but please tell me when you do."

Now I have a much better answer. Independent Cancer Patients' Voice allows patients and carers the chance to offer our own views on what patient benefit actually is (and often it is simply in being told what other options and choices there may be) and to set up a group where researchers could come for practical help and genuine encouragement, offered with a critical eye but in a friendly spirit, at any stage of their work.

That of course includes helping to publicise their results and helping to deliver improved cancer services. ICPV is a Voice that is speaking clearly and firmly and one that is being heard.

"Much of what we do in the field of translational research has the primary objective of improving patient care. Clearly, to do this requires both the support of and interaction with patients. IPCV provides an informed and positive input into research in the clinical setting. By influencing both scientific processes and the practical steps required to facilitate patient oriented research ICPV ensures that researchers can focus their work on what is truly important to the patient."

John Bartlett
Professor of Molecular Pathology, Endocrine Cancer Group, University of Edinburgh

About us

Independent Cancer Patients' Voice (ICPV) is a patient advocate group promoting the value of medical research to public health and the national economy.

We started in July 2009 with a group of breast cancer patients with a keen interest in research. We all felt strongly that we wanted to be part of improving the outcome for future patients.

With a range of professional backgrounds and of patient experiences, most of us had already been involved with breast cancer charities and three of us were members of the NCRI Breast Clinical Study Group.

Together we felt 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. And so, ICPV was born – to provide a forum for learning and debate through which patients could have an effective independent voice in research.

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

Background

There are many types of cancer and many people living with cancer. Clinical trials are at the heart of the great improvements in survival that have been achieved over recent decades.

Cancer patients volunteer to take part in clinical trials in order to improve outcomes for all types of cancers, and to try out new methods of treatment which could increase their life expectancy and could prevent their cancer recurring. Trials are also of great benefit to future cancer patients.

Currently only 14% of adult cancer patients take part in clinical trials. Research could make much more rapid progress if this number were increased.

Breast cancer is an excellent example of high quality clinical research leading to improved treatments and a substantial increase in survival after treatment. Earlier diagnosis has helped, but the high quality of UK clinical research has been very important. There is now a much greater understanding of the biology of breast cancer and the need to tailor treatment to the individual patients.

" I am delighted to see that ICPV has reached its first birthday. It is extraordinary that anyone involved with cancer research could have even contemplated doing so without the opinions of the people most affected namely patients. I for one have valued the intelligent, thoughtful, and well-argued input of many ICPV members. Thanks to you all and many congratulations. Please keep up the good work keeping us all grounded and focussed on what matters."

Professor Lesley Fallowfield
Director Sussex Psychosocial Oncology Group

There is so much more to be learned about cancer. But clinical trials are expensive and they need to be targeted effectively in order to have the greatest impact. We have heard from many cancer patients who would liked to have had the opportunity to participate in trials but were not given information. Patients need to be better informed about current research; many more patients need to be offered entry to clinical trials; and clinical research needs input from the unique perspective of the patient, especially if researchers wish to encourage more cancer patients to become cancer trial participants.

Our aims

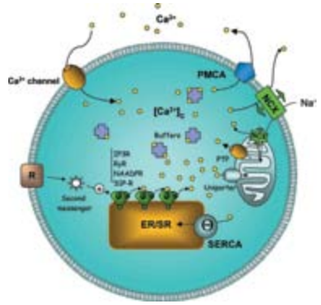
Our aim is to improve existing treatments for every cancer patient and to help the development of new treatments by bringing the voice of patients into clinical research.

We want to be an effective independent voice for cancer patients in research in the UK, communicating the patient perspective effectively to researchers and clinical trial designers. We believe that this will help to increase accrual to clinical trials and to improve the experiences and outcomes of cancer patients. ICPV is a new medium of effective communication between patients, clinicians and scientists.

Our ultimate aim is the development of improved treatments and quality of life for all people with cancer.

Communication also takes place via:

- Our website, **www.independentcancerpatientsvoice.org.uk**. This is regularly updated with two-way information, enabling members to share their experiences and supply information to clinicians.
- The hosting of meetings between patients, clinicians and researchers
- The provision of other means of communication including a Google discussion group
- The promotion of "Guiding Principles" to support shared understanding between patients, clinicians and researchers.



What we do

We provide 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 offer training opportunities to cancer patients to improve their clinical knowledge and research awareness and help them communicate on an equal footing with clinicians and researchers. We encourage experienced cancer patient advocates to become members of ICPV.

We engage with clinicians and researchers in a variety of ways including our 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

We are independent of established UK cancer charities but we work closely with them. Some of us are members and volunteers of other charities; 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 (at the NCRI, NCIN and elsewhere) with clinicians and clinical researchers in order to improve clinical research and outcomes for all cancer patients.

ICPV was set up by breast cancer patients and much of our activity in 2009-2011 has mostly focused on breast cancer. We are now broadening our involvement to include other cancers and we have recruited new members with experience of other types of cancer. A major focus now is on growing our membership and adding to our collective skills set.

Our Members

In August 2011 we have 30 members from around the UK.

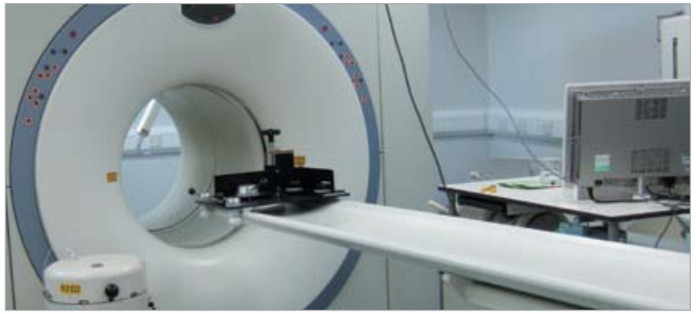
All of us are either cancer survivors, or have cared for someone with cancer. Some of us have had both those experiences, and several of us have been trial participants.

We have a wealth of patient experience and a rich mix of professional expertise, with backgrounds in academia, business, local government, education, corporate communications, healthcare 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".

We have all received some level of training, mentoring and support as advocates. Several of us have received specialist education provided in the US by the National Breast Cancer Coalition Fund – Project LEAD. We provide training for all our members to enable them to fulfil their advocacy role effectively. Some of us have become trainers ourselves, including training roles at academic institutions and for research staff in Clinical Trials Units and cancer networks.

Our Trustees

The brief profiles of our Trustees demonstrate the wealth of experience at the core of our organisation. Our growing membership adds to this unparalleled experience.



Maggie Wilcox

Maggie was diagnosed with breast cancer in 1997.

With a background in health visiting and palliative care, Maggie has been involved with a variety of cancer organisations since her diagnosis – including the UK Breast Cancer Coalition, Breakthrough Breast Cancer, Breast Cancer Care and Macmillan. She is at present a lay representative for the new Breast Tissue Bank launched by Breast Cancer Campaign.

She has advocacy experience nationally with the NCRI Breast Clinical Study Group, the UK Breast Intergroup, NCRN Consumer Liaison Group as well as in working groups for the NCRI (Portfolio Balance), Cancer Reform Strategy and the National Cancer Survivorship Initiative. At the local level Maggie is a member of the SWSH Cancer Network Breast Site Specific Group and the Cancer Partnership Research Group. She is a lay member of several Clinical Trial Management and Working Groups.

Maggie has spoken at an Age Concern Conference, King's Fund Training events, The NCRI Conference, CLG meetings and a Surrey University course. She has attended training sessions provided by NCRN, Breast Cancer Care, Breakthrough and Macmillan, and has undertaken Project LEAD training in the USA and in Paris.

Jill Bartrop

Jill was diagnosed with cancer of unknown primary in 1999.

Jill has a background in Child and Adult protection work and now works as a qualified lip-speaker with the deaf community. She is also a member of South Yorkshire Police Authority.

She became interested in cancer research following her diagnosis and is a patient member of the NCRN Breast Cancer Clinical Study Group and the North Trent Research Partnership Group.

She provides a patient perspective at local, regional and national levels and speaks at conferences both locally and nationally.

Jill was awarded the MBE in 2004 for her work with the NHS in North Sheffield and for her involvement with the deaf community.

Adrienne Morgan

Adrienne was diagnosed with breast cancer in 2005 and secondary breast cancer in 2010.

Adrienne is a PhD medical research scientist and worked for 20 years in academia and industry. She now works in the cancer charity sector, having spent three years as the staff scientist at Children with Leukaemia, and then a year as the secretariat for Cancer52 – an umbrella organisation that represents the less common cancers.

She has worked informally as a patient advocate with Breakthrough and Breast Cancer Campaign since her diagnosis. Most recently she has been involved with Campaign's new Tissue Bank initiative. She is a lay member of several Clinical Trial Management and Working Groups and a familiar independent patient voice in Q and A sessions at cancer research conferences.

Daphne Havercroft

Daphne was diagnosed with breast cancer in December 2003.

She has a wealth of experience in patient advocacy: she first became involved in 2005 when she joined Breakthrough Breast Cancer Campaigns and Advocacy Network, believing that patients should have the opportunity to be partners with clinicians and healthcare professionals, rather than passive recipients of healthcare. She completed Project LEAD training, including Clinical Trials training, in 2008.

Internationally, she represented Breakthrough in Washington DC at the 2007 National Breast Cancer Coalition's Annual Advocacy Conference; she participated in the San Antonio Breast Cancer Symposium the same year and is a member of the National Breast Cancer Coalition. Nationally, Daphne is a member of the NCRI Breast Clinical Studies Group and the NCRI Consumer Liaison Group.

Locally, she is involved in South Gloucestershire Local Involvement Network (LINks) – using her knowledge and experience to make recommendations on improvements to local healthcare services.

Daphne has previously been a Peer Support Volunteer for Breast Cancer Care, providing telephone support to women diagnosed with breast cancer. She was a co-investigator for a Systematic Review of Assessment of Cosmesis after Breast Reconstruction Surgery (*Annals of Surgical Oncology Volume 1 / 1994 - Volume 18 / 2011*).

Daphne works as a Project Manager for a Global IT Services Corporation and has found her professional skills invaluable for patient advocacy.

Carolyn Morris

Carolyn was diagnosed with breast cancer in 1999; it recurred in 2009.

A counsellor and careers psychologist by background she is involved locally, in Sussex Cancer Network's Partnership Group, and further afield in Cancer Peer Review. She is currently part of Thames Cancer Registry's Advisory Group, the National Collaborating Centre for Cancer's Board and the National Cancer Research Network group on Impact. Her strongest research interests are in supportive care; as part of the Compass Research Collaborative she helped run Master Classes in Involvement for researchers in supportive and palliative care.

She has worked on a number of evaluations of user involvement – including for Macmillan Cancer Support, the UK Clinical Research Collaboration and a study looking at the impact on patients and carers of being involved in cancer research and service improvement.

Hilary Blackburn

Hilary was treated for triple negative breast cancer in 2002.

Hilary became involved in NHS partnership work chairing and co-chairing the Surrey, West Sussex and Hampshire (SWSH) NHS Cancer Network's User Partnership Group from early 2003. She has represented patients at local NHS PCT Policy Board level, Clinical Advisory Groups, Local Research Partnership Groups and at the SWSH Breast Tumour Group meetings for the last six years and is currently a member of the SWSH Network Radiotherapy Group.

She has undertaken research reviews as a panel member for Macmillan and has taken part in various working groups and advisory panels for both government and charitable organizations.

She represented the 'lay' perspective as a Board Member for the NCRI from 2007 to 2011 and is currently a member of the national CTRAD radiotherapy research initiative and an executive group member. She also sits on the NCRI Conference Planning Group for 2011/12.

Previously she has worked on studies for Breast Cancer Care as part of their User Involvement Strategy Advisory Group and has conducted patient and carer interviews and focus groups for the 'Find a voice' study.

Hilary's professional background lies in international corporate communications and branding within the exhibitions and events industry.

Mairead MacKenzie

Mairead was diagnosed with breast cancer in 2002.

She was treated initially with chemotherapy, followed by mastectomy with immediate reconstruction. This was followed by radiotherapy and five years of Tamoxifen and Arimidex. Since her treatment she has developed mild lymphoedema and capsular contraction in her reconstruction, necessitating further surgery. This has prompted her to feel strongly about the issues and potential problems arising from the long term effects of cancer treatments.

Having benefited from Breast Cancer Care's peer support prior to her surgery, Mairead became a 'One 2 One' volunteer in 2004 and later joined their Service Users' Research Partnership. She now sits on their main Research Committee.

She is also a patient representative on the South West London Breast Tumour Working Group and has been involved with a number of their projects looking recently at the implementation of the Cancer Reform Strategy and developing new methods of follow-up.

Mairead has professional background as an information scientist/ librarian and has worked mainly in the medical, scientific and technical fields. For many years she was the librarian for the Royal Pharmaceutical Society of Great Britain. She currently works freelance.

" ICPV is a very professional and well organised group. The group has organised a number of successful discussion forums involving Clinicians, Researchers, Patients and other stakeholders. At the event I attended, there were very open and constructive discussions about potential future research proposals ensuring that patients' thoughts and ideas were aired and considered in earnest."

Julia Simister
Research Network Manager Royal Surrey County Hospital NHS Trust

Our other members include

Christine Allmark

- background in higher and further education with previous personal experience of chronic health problems and related voluntary sector activity
- diagnosed with head and neck cancer in 2002
- went on to become a tutor in medical communication skills and formerly employed in academic health research at the University of Leeds
- employed as User Research Lead and Research Assistant within the Macmillan 'Home but not Alone' study
- ongoing research involvement includes consumer advisor to NIHR Head and neck 5,000 project, based at University of Bristol
- PPI memberships: NCRI CLG and Head & Neck CSG, NCIN Head & Neck SSCRG
- Local and regional cancer network user partnership groups

Alero Dabor

- LLM Graduate, currently an academic research student in Socio-legal studies, diagnosed with breast cancer in 2006
- main interest is in Vocational Rehabilitation for cancer survivors
- on the Panel of Experts for Vocational Rehabilitation with Macmillan Cancer Support
- also interested in the hard-to-reach groups for clinical trials
- undertook Project LEAD Training course in Cancun in 2011

April Matthews

- Originally a copywriter, then a social scientist graduate, was successfully treated for breast cancer in 2001
- Now has side-effect of lymphoedema
- main research interest lies in Psychosocial effects of diagnosis and treatment of cancer
- involved in the TARGIT trial which takes her to conferences and meetings in the UK and Europe
- recently joined the management board of the Breast Cancer Campaign Tissue Bank

Alison Walker

- MBA graduate, diagnosed with breast cancer late 2007
- involved with the SUPREMO trial since June 2008 as the patient representative
- member of Breast Cancer Care's Service User Research Partnership
- involved with review of the breast screening service for Scotland
- involved with the Cancer Care Research Centre, based at Stirling University
- attended Project LEAD training course in Washington DC in 2010

Richard Stephens

- Background in journalism, education and local government
- Hodgkin survivor
- Trainer/facilitator – Twocan Associates (NIHR staff training)
- Trainer/facilitator – NCRN (staff training, including CTUs and network nurses and researchers)
- NCRN Lymphoma CSG Sub-Groups (for Hodgkin and for Biology/ Translational studies)
- NCRN workstream – Impact of Patient and Public Involvement
- NCRN/NCRI PPI Steering Group and Consumer Liaison Group
- NCIN - Haematology Site-Specific Clinical Reference Group and Scientific Advisory Group
- MRC CTU trials protocol review committee

Full membership list August 2011

Christine Allmark
James Ashton
Nigel Baker
Jill Bartrop
Elizabeth Benns
Hilary Blackburn
Alero Dabor
Joanna Dugher
Hilary Essen
Patricia Fairbrother
Chris Finch
Emma Freeborn
Jacqui Gath
Margaret Grayson
Daphne Havercroft
Linda Larter
Mairead MacKenzie
April Matthews
Jean McGregor
Sara Mckenna
Caroline McManus
Adrienne Morgan
Carolyn Morris
Debbie Nicholson
Richard Stephens
Ali Stunt
Vonny Tarapore
Alison Walker
Maggie Wilcox
Rose Woodward

Review of Activities

This is our first review of our activities and it covers the period from our inception in July 2009 to June 2011.

Our fundamental aim is to improve clinical research by providing the patient perspective. We believe that this leads to better recruitment to clinical trials and faster improvements in treatments and outcomes for all cancer patients.

We meet our aim in a variety of ways:

- Organising study days
- Collaborating on clinical studies
- Responding to consultations
- Attending and speaking at conferences
- Raising awareness and encouraging participation

Organising study days

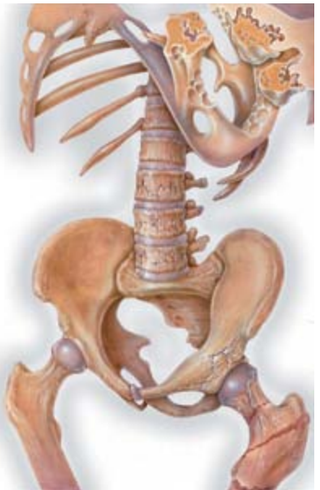
Our study days enable patients to get involved in clinical research by meeting academics and clinicians who work at centres of excellence in cancer research. The aim of the study days is two-fold: we want to increase patients' clinical knowledge and we want to help the academics and clinicians to understand the patients' perspective. The days also enable and empower patients to speak as patient advocates and research partners with the professionals.

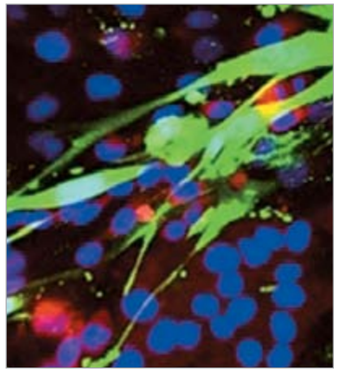
Leeds, July 2009

Our first study day was held at the Leeds Institute of Molecular Medicine (LIMM) in July 2009. Hosted by Dr Val Speirs of the LIMM Breast Research Group, the day involved 23 participants including patients, research nurses, scientists and clinicians.

Presentations were given by Dr Speirs and colleagues from across Leeds on a range of topics including the collection and use of tissue in breast cancer research, the development of laboratory models to study breast cancer, breast reconstruction and the study of radio-resistance in breast cancer. Professor Rob Coleman talked about breast cancer and bone health. Aidan Hindley from the Leeds Tissue Bank gave a very interesting presentation about GIFT, whole body donation at the end of life, as a resource for doctors and scientists to increase their knowledge and treatment of disease.

Dave Ardron, Chair of the NCRI Consumer Liaison Group, spoke to us about the NCRI and welcomed the formation of ICPV. Lucy Ziegler, a Research Fellow at St James' Institute of Oncology, consulted participants on the measures of emotional distress that she is developing with the COMPASS collaboration.





"ICPV provides an excellent and much needed forum for the cancer patient to voice their opinion on UK medical research. As a breast cancer researcher I believe engagement with patient advocates really helps focus the reasons behind why we are doing research and it was a pleasure for me to host the first ICPV study day."

Dr Valerie Speirs
Reader in Cellular Pathology, Breast Research Group, Leeds Institute of Molecular Medicine and St James's University Hospital

www.independentcancerpatientsvoice.org.uk

I was very proud to discover that my lymph nodes had been used to develop a new way of seeing affected sentinel nodes during surgery – preventing unnecessary lymph node removal

I assumed all tissue taken at surgery is banked – but it isn't – it just gets thrown away!!!

I do not know of a patient who would not agree with a request that their tissue be used in research. To think that the material is thrown away or stored and not recorded in any useful way is a terrible waste and should not happen.

Take it. It's no use to me but it might benefit someone else

After my lumpectomy and radiotherapy I was one of those rare people who needed a mastectomy. My breast tissue could have been very valuable for research and it was just thrown away.

The night before I was due to have my ovaries removed a doctor came and asked me if they could be used for research. It made losing them so much more acceptable.

My chemo before surgery was so good no tumours could be found by scanning, but it was still felt best for me to have a mastectomy just in case there was some left. Research on my breast tissue could have shown that the chemo had cleared the cancer and reduced radical surgery for others in the future. But it was just thrown away.

London, November 2009

Professor Louise Jones, Professor of Pathology at Barts Cancer Centre, hosted our second study day in November 2009.

Benoit Aigret, Head of the Cancer Prevention Trials Unit (CPTU) at Barts, gave an interesting overview of the work of the CPTU. He talked about three new breast cancer studies which are now underway including LATTE (Long-term Anastrozole vs Tamoxifen Treatment Effects); Out of Hours (A randomised study of the effect on attendance rates at breast screening of weekend and out-of-hours appointments); and FH01 blood (Investigation of a molecular marker of early breast cancer in women less than 50 and at high risk of breast cancer).

Stephen Duffy, Professor of Cancer Screening at the Wolfson Institute of Preventive Medicine, gave a presentation on the UK breast cancer screening programme. He discussed the effect of the screening programme on mortality rates, on incidence rates and tackled the thorny issue of over-diagnosis.

Other topics of the day included *Geographic Influences on Breast Density* and *Tissue Donation Consent Issues – A Debate*.

Cardiff, May 2010

We held our third study day in May 2010 at the Velindre Cancer Centre in Cardiff, hosted by Professor Peter Barrett-Lee, Consultant Clinical Oncologist, Professor of Oncology in the School of Medicine at Cardiff University, and lead specialist in breast cancer at Velindre NHS Trust.

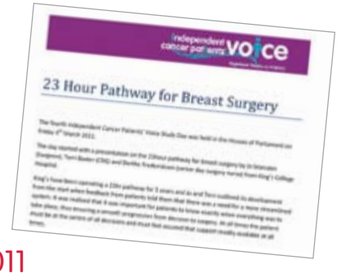
Professor Barrett-Lee spoke about the Value of patient input into research; Professor Malcolm Mason talked about Clinical trials and trial design; Denize Vaile covered *Radiotherapy led follow-up and how it works*; Dr Jacinta Abraham spoke about *Secondary/metastatic breast cancer* and Professor Sir Martin Evans gave a presentation on *Genetics*.

" As a Cancer Professionalworking in the field of Breast Cancer Clinical Trials, the members of ICPV have been invaluable in helping us to understand how we should design the next generation of trials in order to be successful. This means patient and lay public involvement at an early stage and ICPV supports its members to do this important work"

Professor Peter Barrett-Lee
Consultant Clinical Oncologist and Interim Medical Director Academic Breast Unit Velindre Cancer Centre Cardiff

" I have been engaging with ICPV over the last two years. The experience has been very refreshing. ICPV is very well organised with a range of very knowledgeable and open minded membership who are clearly committed to engaging with the breast cancer research community to provide not only support to breast cancer research but, more important, providing a lively channel for helping design studies to incorporate the needs and views of patients. The enthusiasm and commitment of the organisation is a great help to researchers battling through the complex process of clinical trial development. This group is now recognised as a key player in shaping new clinical trials in breast cancer in the UK."

Daniel Rea
Senior Lecturer in Medical Oncology, CRUK Clinical Trials Unit, School of Cancer Sciences, University of Birmingham



London, March 2011

Our fourth study day was held at the Houses of Parliament.

The day began with a presentation on the 23 hour pathway for breast surgery by Jo Marsden (Surgeon), Terri Baxter (Clinical Nurse Specialist) and Dorothe Frederisksen (senior day surgery nurse) from King's College Hospital. They outlined the development of the pathway, which has been operating at King's for five years. Following on from this Beth Jackson (CNS) from the Royal Marsden summarised the implementation of the pathway into the Royal Marsden at Fulham and Sutton which was due to 'go live' imminently. A lively discussion followed. Several participants had undergone surgery via the 23 hour model and all felt very positively about it. We produced a discussion paper which is now on the DOH Improvements site.

A discussion on clinical trials followed, with short presentations on PARP Triple Negative (NEPTUNE) (Dr Jenny Glendenning, King's College Hospital); DCIS (Claire Gaunt, Adele Francis and Dan Rae, Birmingham); SentiMag (Michael Douek, King's); and Management of Vaginal Dryness/Atrophy post-treatment for ER+ Breast Cancer using Essential Oil Pessaries (Jacqui Stringer, Christies).

As well as being of great benefit to our members, our study days have gained appreciation from clinicians and researchers, who also find them a valuable learning experience.

Collaborating on clinical studies

Our members are involved in the design and running of a number of clinical studies, helping to ensure that they are targeted effectively. 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.

We get involved in many different ways. For some studies, we input into the very earliest stages of trial development, contributing to the development of funding proposals. We read and comment on trial protocols and on patient information materials to make it more likely that patient will enrol. Our members sit on the steering committees of many active trials to ensure that the patient perspective is considered.

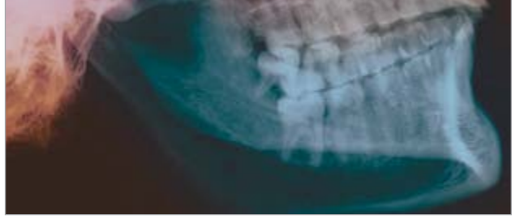
In 2009/10/11 our members collaborated on a wide range of studies, including: **OPTIMA**, a new clinical study that should ultimately reduce the amount of chemotherapy given to breast cancer patients; **IMPORT HIGH & LOW** (two trials looking at different ways of giving radiotherapy to high- and low-risk breast cancer patients); **POETIC** (a trial looking at whether having hormone therapy before and after surgery improves the outlook for post-menopausal women with breast cancer); and **iBREAST** (a trial seeking to determine whether innovative alternative follow up methods are equivalent to traditional specialist hospital-based follow-up in terms of survival and patient perception of living with cancer).

We have supported and continue to work with the Breast Cancer Campaign's tissue bank board of management and tissue access committee.

With our members have been involved in a number of clinical trials. We describe a selection and list others.

" I am personally very grateful for the ICPV; my experience has been that they are a very proactive group of people who have made it their business to keep abreast of new work within the field of cancer research and as such are a huge asset to the development of such work as they are in a position to make it clinically relevant to the people who count - the patients! Please keep up the good work!"

Jacqui Stringer
Clinical Lead for Supportive Care Services,
The Christie NHS Foundation Trust



TACT trial

Consent to use of tissue

The TACT trial set out to assess the benefits of using docetaxel as a follow-up to standard chemotherapy in women with early breast cancer. More than 4,000 patients were recruited and donated tissue samples for subsequent biological studies.

The investigators ran into difficulties when MREC proposed that the biological studies constituted a new study and that patient consent would therefore be sought for use of the samples, seriously hampering the progress of the research. ICPV members joined with the research team and others to successfully argue that the biological studies should be treated as an amendment and not as a new study, so that renewed consent would not be required.

Having donated tissue ourselves, and based on our extensive discussions with other breast cancer patients, we argued strongly that patients expect their samples be used to maximum effect to benefit others and feel great frustration when delays are caused by over-regulation.

We were delighted that the amendment was reconsidered and approval given, meaning that the biological studies could proceed without further delay.

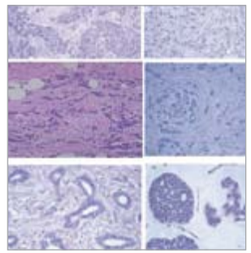
BISMARK

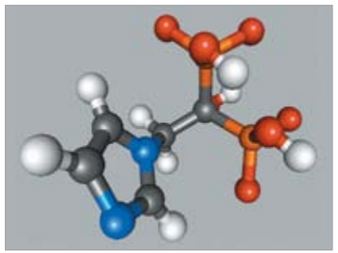
Cost-effective use of BISphosphonates in metastatic bone disease - a comparison of bone MARKer directed zoledronic acid therapy to a standard schedule

ICPV member Jacqui Gath was involved in the BISMARK trial, which looked at the use of zolendronic acid (ZA) in metastatic bone disease – and the effect, on treatment outcome and quality of life, of tailoring dose to the requirements of the individual according to level of bone markers.

Jacqui was concerned about the risk of patients developing osteonecrosis of the jaw (ONJ) as a result of taking zolendronic acid. Prompted by Jacqui's concerns, the steering committee for BISMARK agreed that patients should be advised to have their teeth examined and to have any necessary treatment before commencing ZA treatment. She helped devise an information sheet for dentists, and patients were advised to tell their dentist about the drug. Any patients needing a lot of dental treatment were not entered into the study.

Jacqui's input is likely to have reduced the risk of patients developing ONJ. It has also resulted in dentists becoming better informed about biphosphates such as ZA – important because they are now regularly prescribed to prevent osteoporosis in post-menopausal women.





" ICPV has worked closely with Warwick CTU to develop a patient booklet and clinic poster for the Persephone Herceptin duration trial which seeks to recruit patients into the standard 12 months Herceptin vs a reduced duration of 6 months. Previously the group successfully challenged the ethics committee decision to split the consent form into 5 separate documents which considerably undermined recruitment into the trial. The ICPV continues to improve clinical trial information and processes, including 'bureaucracy busting' for tissue collection and consent. Academic-led (i.e. non-commercial) research questions are equally important to improve quality of life and reduce toxicity as compared to the pharmaceutical trials comparing new drugs."

Professor Janet Dunn
Deputy Director of Warwick Clinical Trials Unit, Head of Cancer Trials, University of Warwick

www.independentcancerpatientsvoice.org.uk

Poetic

POETIC

Peri-Operative Endocrine Therapy Individualising Care

The POETIC trial is analysing whether hormone therapy before and after surgery improves the outlook for post-menopausal women with breast cancer. It is a very important and large trial involving surgeons as well as oncologist researchers.

Maggie Wilcox was invited to be a member of the trial working group and then the trial management group. Her input has helped to ensure that the trial is patient-oriented and that all possible care is taken to reduce any anxiety with respect to entry to the trial and timing of consent and tissue sampling.

At the launch of POETIC, Maggie was invited to join the clinician discussion. A surgeon stated that the trial should not be mentioned at the time of diagnosis as this would exacerbate an already stressful experience. Maggie was able to counter this by stating that not mentioning the trial was denying patient choice and that, providing it was approached in a sensitive way, most patients would be happy to consider participating in a trial.

Maggie has continued to seek opinion from other patients in local and national groups on various queries, which have arisen during the trial. For example, she was asked to seek wider patient opinion about entry to more than one trial after REC approval for a trial was conditional upon patients not being proposed for multiple concurrent trial entry. She reported widely-held strong views amongst most patients that patients do not appreciate being shielded in this way and do not consider themselves to be too vulnerable to make decisions. Feedback from patients later in the POETIC trial confirmed this and that patients generally welcome being approached to donate tissue and to consider trial entry.

2011 THE YEAR OF RADIOTHERAPY

IMPORT High and Low plus IMPORT IGRT

The IMPORT trials are looking at different ways of giving radiotherapy to breast cancer patients.

IMPORT Low has now completed recruitment and is to test partial breast radiotherapy delivered using intensity modulated techniques following complete local tumour excision in women with low-risk early breast cancer

IMPORT High is still recruiting and is to test dose escalated intensity modulated radiotherapy after conservation surgery for early breast cancer in women with higher than average local recurrence risk

IMPORT IGRT aims to test whether x-ray imaging facilities on modern radiotherapy (RT) machines are able to monitor the exact position of internal organs within the RT beam during treatment and therefore allow margins of healthy tissue around the tumour bed to be reduced. This could reduce the rates of moderate to severe fibrosis which may arise in healthy breast tissue exposed to RT.

Maggie Wilcox has been a member of the trial management group from the early stages of IMPORT High and Low and has contributed to a Patient Information Sheet and newsletters, and given a patient perspective on use of data collected and acceptability of trial entry. Through taking part in Network Peer Review she was able to provide an example of a letter to patients with "footer" advising patient to ask about trials that may be suitable for them.

This trial has highlighted that centres which do not join breast cancer RT trials tend to offer outdated and sub-optimal treatment to their local populations. Experience of using tumour bed markers is proving this to be a real benefit in planning and should become standard. There is a risk to accrual in IMPORT High because of resource constraints and capacity issues and as most future RT trials will require this level of complex planning, the UK runs the risk of not being able to keep up with the rest of the world and of denying more accurate and effective treatment to UK women with high risk of local recurrence.

"ICPV is a group of people from a broad background who have in common the experience of being diagnosed and treated for cancer. With this experience they provide an important and constructive contribution in many settings, on the clarity and relevance of written information, on the acceptability or otherwise of clinical studies, on the need for better information and improved understanding in different situations. ICPV alert the medical profession to the patient perspective and as such provide a critical contribution to the improvement of medical research and patient care."

Louise Jones
Professor of Pathology, Institute of Cancer,
Barts and the London Medical School

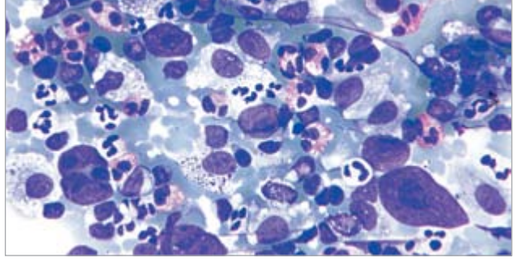
www.independentcancerpatientsvoice.org.uk

eRAPID

electronic patient self-Reporting of Adverse-events: Patient Information and aDvice

eRAPID aims to develop, introduce and evaluate a system for patients to self-report adverse events during and after cancer treatments. It is expected that this will encourage self-management of mild adverse events and reduce hospital visits, whilst providing rapid alerts for urgent management of severe events.

Carolyn Morris is a member of the Project Advisory Group and April Matthews is a member of the Scientific Steering Group.



HOLySTIC

Hodgkin Lymphoma, A UK Screening Trial for Treatment Induced Second Primary Lung

This is a proposed pilot study based at The Christie, being considered for funding by the National Awareness and Early Diagnosis Initiative (NAEDI). The proposal is to look into screening survivors of Hodgkin's Lymphoma for lung cancer, concentrating initially on ex-smokers over 50, statistically at high risk.

Richard Stephens is on the Trial Management Group, partly because of his links with the lymphoma clinical studies group, partly because he sits on one of the NAEDI workstream groups, and partly because he is Hodgkin survivor, aged over 50, and an ex-smoker.

" Independent Cancer Patients' Voice is making a major contribution to the design and implementation of clinical cancer research within the UK. From personal experience, I know that their advocates have played a most important part in the current success of the UK pre-operative POETIC trial in early breast cancer and their advice was crucial in influencing decisions made both by funding bodies and ethical committees. All power to them!"

Professor Ian Smith
Consultant Medical Oncologist, Professor of Cancer Medicine,
The Royal Marsden and the Institute of Cancer Research.

We have contributed to a wide range of other clinical studies, including:

ANCHoR trial
April Matthews sits on the DMEC committee of this trial

DCIS RCT
Discussed at our Westminster study day. Daphne Havercroft, Elizabeth Benns and Maggie Wilcox are on the working group for this trial

EPAN
Richard Stephens chaired the User Reference Group for this trial

EPHOS-B
Mairead Mackenzie was involved with PIS reviews and attended the launch meeting

FAST-Forward
Carolyn Morris and Sara McKenna are the consumer reps on the trial management group for this radiotherapy trial

GUIDE-Care
Carolyn Morris is on the advisory group

HeartSpare radiotherapy study
Mairead Mackenzie is on the management team

iBREAST
Maggie Wilcox is a member of the working group for this trial

NEPTUNE
Hilary Blackburn is a member of the working group for this trial

OPTIMA
ICPV provided detailed comments and Adrienne Morgan is a member of the working group for this trial

PATH
Mairead Mackenzie contributed comments prior to submission

Persephone
ICPV members helped develop a patient booklet and clinical poster

QUEST
Mairead Mackenzie is on the trial management group; April Matthews was involved in the early days of preparation

SentiMag
April Matthews commented on the initial protocol for this trial

SUPREMO
Alison Walker is patient representative

TOMMY
Jill Bartrop is a member of the steering group for the TOMMY trial

TARGIT
April Matthews has been the patient advocate on the International Steering Committee of the TARGIT trial

Breast Cancer Campaign Tissue Bank
Mairead MacKenzie, April Matthews, Adrienne Morgan and Maggie Wilcox work with the tissue bank board of management and tissue access committee.

"Before ICPV the involvement of patient advocates in designing clinical trials was a rather hit and miss affair. It was not at all unusual for cancer trials to be written with no input from patients at all. ICPV members are fully involved in the design of our current breast cancer trial, advising on all issues from acceptable terminology in patient information sheets to actual trial design, They are an integral part of the team and their support and enthusiasm benefits both the clinicians struggling to design the 'right' trial and the patients who will be participants in them. They have harnessed a huge untapped resource and UK cancer trialists are very pleased to have a formal route for involving patient expertise."

Adele Francis
Consultant Surgeon & Honorary Senior Lecturer, Surgical Oncology, University Hospital Birmingham

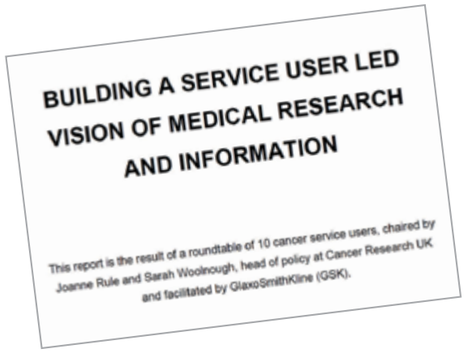
Responding to consultations

As well as providing input on clinical studies, ICPV members respond to consultations on other aspects of cancer care and research, helping to ensure that the patient perspective is taken on board in all of these consultations.

We have responded to a number of consultations this year, including the following:

Clinical research in the NHS - Building a service user led vision of medical research and information

In light of the Department of Health's current consultations into information and choice, we worked with 10 other service users to explore the changes required to the provision of information on medical research. ICPV members organised by Joanne Rule for GSK and also involving NCRI CLG members produced a report 'Building a service user led vision of medical research and information' , which we presented to Earl Howe, the Undersecretary of State for Health, in January 2011.


BUILDING A SERVICE USER LED VISION OF MEDICAL RESEARCH AND INFORMATION

This report is the result of a roundtable of 10 cancer service users, chaired by Joanne Rule and Sarah Woolnough, head of policy at Cancer Research UK and facilitated by GlaxoSmithKline (GSK).

The report identifies real concerns and difficulties faced by service users in accessing useable and accurate information about medical research. It then goes on to identify possible solutions to some of these issues from the unique perspective of the service user.

The report builds a picture of how the information revolution can help relevant research to become part of the way the NHS carries out its core business, to the benefit of patients and to the enterprise of UK clinical research. For these benefits to come about, increased awareness and access to high quality information is needed. Perhaps most importantly, every person affected by cancer should be told by a health care professional about the research that is relevant to them.

Earl Howe gave a detailed response to our report, setting out the ways in which the Department of Health is working to address our recommendations and underlining their commitment to empowering patients. We welcome Lord Howe's assurances and we are pleased that several of the report's suggestions have emerged for wider consultation and comment as part of the Government's wider health reforms. We will be watching carefully to see what happens next.

" ICPV is an important addition to the chorus of voices in cancer research and activism, maintaining as it does its grass roots character and focus on advocacy, undiluted by the wider political agendas often associated with larger patient and research-focused organisations. It follows the pattern of working closely with the medical profession, but in the spirit of mutual learning. Two ICPV meetings that I have attended have provided interesting, and I believe successful examples of a productive interplay between biomedical researchers and active patients and participants in research."

Dr Norma Morris,
Research Fellow, Dept of Science & Technology Studies, UCL

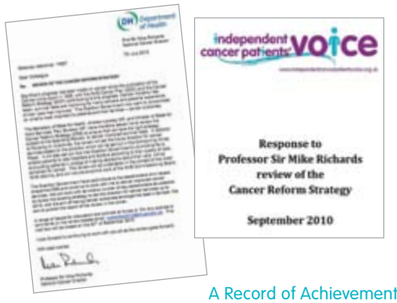
Review of the Cancer Reform Strategy

ICPV contributed to the review of the Cancer Reform Strategy (CRS) conducted by Professor Sir Mike Richards. The review aims to ensure that we have the right strategy to deliver improved survival rates for cancer, subject to restrictions imposed by the Spending Review.

Our detailed response drew extensively on our experience as patients. There was very clear agreement amongst ICPV members on our priorities – acknowledging the improvements that have resulted from the CRS, whilst recognising the need to add to the pace of these improvements.

Amongst other issues, we highlighted the important role of Cancer Networks in improving collaboration between research and treatment, resulting in improved outcomes for patients – and emphasised the need for proper funding. We also underlined the importance of Clinical Nurse Specialists for all tumour groups – and the need to protect and enhance this role, as well as providing for patients with less common cancers and those with secondary disease. Similarly we emphasised the importance of multi-disciplinary teams, which need to be allocated sufficient time and administrative support.

A copy of our full response – which was submitted in September 2010 - is available on our website. We are pleased that the Independent Cancer Patients' Voice was one of the voices that helped persuade the Government to retain funding for cancer networks and to continue with Multi Disciplinary Teams.



A Record of Achievement 2009-2011

Academy of Medical Sciences

In 2010, the Academy of Medical Sciences (AMS) was commissioned by Government to undertake an independent review of the regulation and governance of UK medical research.

We responded to a call from the AMS to respond to proposals in the Department of Health's report on arm's-length bodies (ALB report) with direct relevance to the regulation of medical research.

We submitted a detailed response. We welcomed the proposals for streamlining regulation and governance of research, including the reduced bureaucracy involved in gaining ethical approval for clinical trials but we were careful to draw attention to public anxiety over data protection issues as public confidence is of the utmost importance.

We underlined the need for continued enhancement and ring-fencing of funds and resources for medical research.

We called for a more balanced assessment by NICE of drugs which become available through research with appropriate weighting given to the views of specialist panel members. Patients who take part in research need to know that any resulting new treatment will be fairly assessed for use in the NHS as well as being available privately.

We ended by reinforcing the importance of bodies such as the NCRI/NCRN, Local Cancer Networks, MDTs, SSGs, CPRGs, Peer Review, Cancer Action Team and the All Parliament Cancer Group. All of these groups actively encourage and facilitate patient involvement in cancer research but they need to be properly resourced. We support the implementation of the recommendations of the AMS Report.

www.independentcancerpatientsvoice.org.uk

UK Clinical Trials Gateway

ICPV members have been involved in development of the UK Clinical Trials Gateway, a new online resource providing comprehensive information about clinical trials in the UK. The Gateway is designed to help both the public and clinicians locate and contact trials. It is an important new addition to the resources available via NHS Evidence.

Professor Dame Sally C Davies, Chief Medical Officer for England, explains: "Phase 2 of the UK Clinical Trials Gateway increases transparency in research and makes it easier for patients, their doctors and carers, friends and families to see what clinical trials are taking place, what each trial is about, where it is taking place and who is running it."

The Gateway is designed to be simple to use. An important aspect is the availability of lay summaries, making the trial information much more accessible to patients, trialists and non-technical readers. This helps the Government meet its commitment to increasing information about studies and will ensure that more patients are made aware of research that is of particular relevance to them.

Go to **www.ukctg.nihr.ac.uk** to use the UK Clinical Trials Gateway. We strongly endorse this initiative. Only 14 per cent of adult cancer patients enter into clinical trials. Research could make much faster progress if the number of patients entering trials could be increased.

Attending and speaking at conferences

Our members represent ICPV at relevant conferences in the UK and abroad – with the aim of putting across the patient perspective. In 2009/10/11 our members attended over 20 conferences in the UK and abroad.

ICPV members may be taking part in conferences by giving presentations about their experiences or they may be there to learn and to engage in debate with clinicians and researchers. Conferences represent an important opportunity for us to raise awareness of the work of ICPV and the assistance that we can provide in research design and conduct. Our members are active participants in Q and A sessions at conferences.

Where possible, members write-up reports of the conferences they attend, to be shared with other members through our web site and active Google group

San Antonio Breast Cancer Symposium

Texas, December 2010

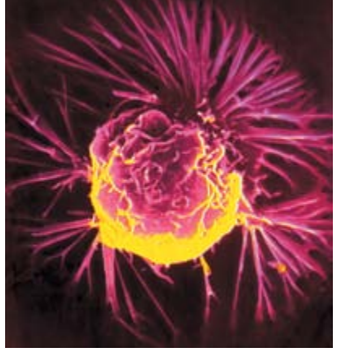
The annual San Antonio Breast Cancer Symposium is the world's leading breast cancer research conference. It brings together research professionals from across the globe to present and discuss progress in breast cancer research and treatment.

Adrienne Morgan, Mairead MacKenzie and Maggie Wilcox represented ICPV at 2010's conference. Adrienne and Maggie funded themselves and Mairead was funded by the Alamo Breast Cancer Foundation, who provide scholarships each year to breast cancer advocates from around the world to enable them to attend the Symposium.

The advocates have their own programme organised around the main event. They are given briefings every evening by key speakers to review and question the day's topics and breakfast sessions to discuss key issues.

Each advocate is given a topic to follow throughout the conference; once home they had to write up this topic for publication in the annual Alamo Breast Cancer Foundation Hot Topics DVD.

Mairead found the symposium an exhilarating – and at times exhausting – experience. It has helped her to better understand the issues affecting breast cancer patients and she feels that it will enable her to better promote the cause of advocacy.



Tri-Network North West Breast Screening Programme Quality Assurance Meeting and Breast Cancer Research Conference

Warrington, November 2010

ICPV member Mairead Mackenzie presented to this meeting, giving an overview of clinical trials from her own, patient perspective.

Mairead was never asked to join a trial when she was undergoing her treatment for breast cancer. She does not know if this is because there was no suitable trial taking place at the time or because her clinicians did not feel able to approach her. As upset and scared as she was at the start of her treatment, she now believes that if she had been asked to take part in a trial and given good information and time to consider, she would have said yes. And she believes the same can be said for most patients. She believes that opting to take part in a trial gives the patient a bit of control at a time when they feel that events are totally out of their control. They can feel empowered because they are making a difference.

Mairead urged clinicians to discuss with their patients the options for taking part in clinical trials, emphasising the importance of having appropriate information to hand and drawing on examples of good practice from other countries.

She also drew attention to the issue of obtaining permission to use tissue obtained from biopsies and surgery in research. She herself was not asked after surgery if her breast tissue could be held for research. She feels that it is a terrible waste to throw simply throw away tissue that could be used in research – and believes that most other patients feel the same way.

She ended by talking about ICPV and emphasising our keenness to help with trial recruitment and patient involvement.

British Oncology Pharmacy Association and the United Kingdom Oncology Nurses Annual Conferences, Manchester

October 2010

Jill Bartrop was asked by Sanofi Avensis to talk at their Symposium on Advances in cancer treatment and the patient perspective in the light of new and more targeted oncology drugs. This allowed her to explore with the audience the advances in targeted therapies and the benefits individual patient based treatments. These advances would enable better targeting of the cancer and reduce side effects on healthy cells. The inherent implications of tailored treatment would be that different patients would experience different regimes. But, the pool of possible candidates would be reduced and patients may find fewer trials appropriate for them to enter emphasising the need for more information to increase patient involvement in trials

Late effects in cancer

Sheffield, March 2010

This two-day conference explored the increasing awareness of late stage effects of cancer treatments. This area of research is in its infancy but is becoming increasingly important as more and more patients survive their primary cancer and then experience side effects often years after their first cancer. Breakthroughs in the treatment of childhood leukaemia mean that these children now live for many years - but can face complications in early adulthood as a result of their cancer treatment.

Surgery, radiotherapy and chemotherapy can leave survivors with long-termconditions such as lymphoedema and lung damage. Sheffield is a leading centre in the study of osteoporosis and those who have had a hormonal cancer are at greater risk of this condition. The cancer burden affects the psychological, social and economic circumstances for patients. The need to inform and support patients to manage their health becomes ever more critical.

Overcoming the unknown: New approaches to diagnosis and treatment of Carcinomas of Unknown Primary

Royal College of Obstetricians and Gynaecologists, London

October 2009

An over concentration on trying to find a primary cancer often subjects patients with an unknown primary to a battery of tests, going from one specialist to another with no long-term package of support. Having this diagnosis means the patient can't be put into a neatly labelled cancer grouping and they can get lost in the system. Life expectancy is often very time limited and research data for this group are poor.

The conference focused on the need for a pathway that clearly gave the clinician the right tools to develop a seamless service. The intention to develop a NICE guidance was discussed plus opportunities to develop more research using International collaboration where possible.

On behalf of ICPV, Jill Bartrop, who was diagnosed with cancer of unknown primary origin in 1999, presented the patient perspective at this important conference.

National Cancer Research Institute

The National Cancer Research Institute (NCRI) is a UK-wide partnership between the government, charity and industry which promotes co-operation in cancer research. Each year the NCRI hosts a Cancer Conference which has become the major forum in the UK for sharing British and international cancer research. The conference brings together the leading experts across all disciplines and is an excellent mix of high-quality plenary speakers, symposia and parallel sessions, including focused satellite meetings and workshops.

Members of ICPV have attended the NCRI conference since its inception. Many patient advocates (including CLG members) receive NCRI bursaries. These are hugely appreciated and enable this very important patient participation. These conferences provide an excellent forum for us to engage in debate with clinicians and researchers and to raise awareness of the work of ICPV and the assistance that we can provide in research design and conduct. At the 2011 conference we have had an abstract accepted and will be presenting a poster on our work.

National Cancer Intelligence Network

The National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research. ICPV members attended the June 2011 NCIN conference and promoted the cancer patients' voice through contributions to the conference, a stand and networking.

Raising awareness and encouraging participation

Cancer diagnosis and treatment can be a very stressful time but we have heard from many patients that they would have liked more information about current research and to have been given the chance to participate – even if only for the benefit of others in the future.

We have produced two leaflets encouraging patients to ask about clinical trials, donation of tissue for research and involvement in local cancer network service development and research, with editable versions available for the addition of local contact information.


every patient is a
Very Important Person
how can you become involved?
independent cancer patients' voice

We distribute these to patients with the help of colleagues in the NHS, the NCRN and other networks. They are also available for download from our website.

Our clinical trials patient to patient leaflet has been approved by the NCRI Haematological Oncology Clinical Studies Group and has been circulated by them to be used for all blood cancer patients and all hospitals where blood cancer patients are treated.

Members' Publications

Our members have also contributed to journal publications over the years. The list below gives a flavour of the range of topics covered:

It's Good To Talk
A comparison of a telephone helpline and website for cancer information.

R Hardyman, P Hardy, J Brody, R Stephens
Journal of Patient Education and Counselling, Vol 57 2005

Targeted intraoperative radiotherapy versus whole breast radiotherapy for breast cancer (TARGIT-A)
*An international, prospective, randomised, non-inferiority phase 3 trial*JS Vaidya et al (including A Matthews) Lancet Vol 376 p91-102 2011

Service User Involvement In Cancer Care: The impact on Service Users
C Morris, P Cotterell, P Beresford & G Harlow Health Expectations Volume 14, Issue 2, pages 159–169, June 2011

Opinion: Patient Engagement
A Morgan Cancer Nursing Practice Vol 10 No 6 p9 2011

The capacity, impact and challenge of service users' experiential knowledge
P Cotterell and C Morris, chapter in Critical Perspectives on User Involvement. Ed. M Barnes and P Cotterell, The Policy Press, in press

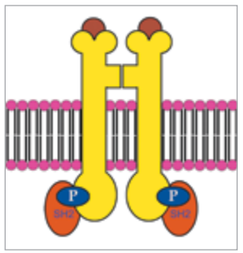
The Future

We held a workshop in May 2011 to review progress and set out an action plan for the year ahead.

We reviewed our experience to date, setting out what has gone well and what challenges we face as we move forward. We are very grateful to Bec Hanley of TwoCan Associates for her excellent facilitation of our workshop. (www.twocanassociates.co.uk)

What has gone well so far?

We have much to be proud of. In just two years we have become a recognised patient advocacy group that is taken seriously by health professionals. We offer an informed voice, independent of other charities. We have a clear vision, which has been communicated effectively, and we have members who feel involved. Our study days have been well-received by all participants and speakers alike, and we have demonstrated impact through our involvement in clinical studies.



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 but 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.

Our plans for the year ahead

External activity

- We will continue to plan, fund and execute study days, aiming to hold at least three study days in 2011/12.
- We will continue to influence breast cancer trials.
- We will seek to influence at least three trials that are not in breast cancer.
- We will attend and have a presence (e.g. by having a stand or offering a speaker) at as many relevant national and international meetings as possible.
- We will identify one or more 'hot topics' and write a paper for the medical / non-medical press.
- We will develop plans to run a summer/ residential school.
- We will develop international advocacy links.

Governance and operations

- We will carry out a membership audit and put together a membership directory to identify and utilise our strengths.
- We will identify clear roles and responsibilities for members.
- We will devise a clearer allocation of responsibilities.
- We will review support structures for members.
- We will develop a fundraising strategy
- We will develop a media and marketing strategy to recruit new members, increase links with research units and also with potential sponsors.

" In the UK one in every six cancer patients is involved in research, representing 42,000 cancer patients per year, the highest level in the world. The research that these patients are involved in has supported many breakthroughs in cancer treatment and service design. Cancer patient engagement across all aspects of the process, from study design through to patient recruitment, dissemination of results and uptake of new interventions, is an essential component of cancer research. Cancer Research UK highly values the important work of Independent Cancer Patients' Voice in enabling valuable engagement between patients and cancer researchers."

Kate Law
Director of Clinical Research, Cancer Research UK

Why We Do This

A friend who used Breast Cancer Care's Forums left this message to be posted there after her death. As a group, we've reflected on her words, which demonstrate the need for organisations like ours to work with the professionals to achieve a better future for people diagnosed with cancer.

"As many of you know I never found anything positive or uplifting about having breast cancer....nevertheless getting breast cancer in the age of the internet has meant a support and information network which was unknown 15 years back. Thank you to everyone who has helped me on these forums since I first logged on in February 2004. Thank you for your support and information, your kindness and laughter. Thank you for great discussions and debates.

My death is but one of the 12,000 deaths from breast cancer this year. More than 45,000 women will face diagnosis in this time. My death is unremarkable. I am 60, not a bad age, even in the west, but still a premature death. Premature too are the numerous deaths from breast cancer of young women with young children. They are there, unnamed in the statistics.

I'd like to think that among those of you reading of my death today are some young women..... newly diagnosed with triple negative breast cancer, the relatively unusual type I had. Today you are very frightened, crying and confused. But I want to imagine that you are going to be all right and that after your treatment is over you will decide to get involved in cancer campaigning...but not for you are the appearances in Fashion shows, not for you fundraising at pink pampering parties, not for you airbrushing the reality of this disease into some designer must have condition. You will decide on a harder more radical route...and a movement will begin to challenge governments, and research scientists, the medics and the charities. You won't be smiling sweetly about good 5 years survival statistics...you'll be saying that 12000 deaths a year is not good enough, that effective prevention and treatment, let alone a cure, is barely off the starting block, that this is awful and it has to change. There was the whisper of such a movement recently...I hope the movement promised comes to fruition with determined committed campaigners.

Winding forward to say 2050 and I hear you talking to your grandchildren about the old days when breast cancer still killed, and generations of women died years too soon. For now in 2050 few people get breast cancer and no one dies of it any more.

This is my hope, my hope for all your futures. Please smile and raise a glass for me in that hope. But avoid soppiness, or any references to bravery and fighting....there were none. Like the thousands before and after me, I simply did the best I could to live as well and as long as I could. We are ordinary women dealt a bad hand by breast cancer."

Two of our founder members died from breast cancer. Maggie Wilcox remembers them:

Jenny Quantrell

Jenny was a very active participant in cancer research both as an advocate and as a recruit to clinical trials and continued to add her views by e-mail after the effects of her secondary disease made it impossible to attend meetings. She had a PhD but said this was not relevant to her advocacy activity - I am not sure about this. Her ability to look through all the verbiage to highlight what were the really important issues for patient benefit may have been due to her professional experience as well as to her natural ability. Her directness, dry humour and intellect meant that she delivered concise, relevant and useful comments on papers, proposed studies and ICPV activities and her contributions to discussions were always valued.

However, she was also very keen to promote more equal access to high quality research and treatment for all patients and particularly access to supportive care including complementary therapies which she found to be of great comfort. She had recently worked with The Haven as she felt they were not just advertising complementary therapies but also working to produce reliable evidence of the value of the therapies available at their centres.

I really appreciated her encouragement and support in setting up ICPV - and also her mentoring my attempts to play golf! Both required time, patience, persistence, learning from others, humour and a refusal to be beaten!

Caroline Sharpe

Caroline was a young mother of two boys who had HER2 positive positive breast cancer and treated with Herceptin before this was easily obtainable in the NHS. She became an active and committed advocate because she wanted all patients to be offered the treatments she could receive through private health care. She attended both the Advocacy Conference in Washington and Project LEAD training run by the National Breast Cancer Coalition in the USA and was disappointed not to be well enough to make it to San Antonio.

Caroline was always totally open and realistic about her prognosis and pushed me to campaign for inclusion of metastatic patients in research meetings and discussions - some researchers and charities are still creating barriers because of their over protectionist attitudes which thoroughly frustrated Caroline. Her secondary disease was diagnosed after a severe car accident and she then had months of intensive treatment for bone and brain mets which meant weeks of inpatient care. She continued to be very active during this time and e-mailed regularly to ask for information or to send details of new research or treatment which she had discovered on-line. Her Project LEAD training was invaluable to her - enabling her to sift out the credible and discard the rest - I was summoned to attend meetings in her room at the Royal Free to update her in person about ICPV activities as well as any new breast cancer news.

Maggie Wilcox remembers:

Jane Andrews

Jane had a healthy scepticism for the mainstream breast cancer charities. Whilst valuing their work in campaigning and support for people with breast cancer, she was frustrated by their bureaucracy and the limitations caused by their need to keep within their chosen strategies. She felt, as we did, that this meant that they sometimes reflected a patient opinion which was selective to fit those strategies and that there needed to be a forum for informed patients independent of the charities and willing to educate themselves to become valued partners in cancer research.

She was an educationalist and researched her own disease from diagnosis with the aim of finding the best possible treatment and whilst accepting the possibility of a poor prognosis for herself, she was also interested in improving the odds for those diagnosed with triple negative breast cancer in the future.

She campaigned for research into triple negative breast cancer and welcomed Breakthrough Breast Cancer's current study being led by Andy Tutt at Guy's and was an active "poster" on Breast Cancer Care's Forum – but, she also gave both charities her constructive criticism. She was very supportive about our launch of ICPV & disappointed that she no longer had the energy to be an active member of a new group.

However, what a valediction she has left to inspire us and ensure that we keep our focus on improving diagnosis and treatment for future patients whilst finding evidence based methods of reducing the incidence of cancer.

"Although Independent Cancer Patients' Voice is a relatively recent arrival in dealing with our national cancer epidemic, ICPV has already contributed significantly to the development of clinical studies, supported (and chaired!) national clinical trials meetings and eloquently added a patient voice to several cancer related activities in the UK. Offering useful advice from a common sense perspective ICPV has already made us think more deeply about how we look after those who have, or have survived, cancer. I for one welcome the involvement of ICPV in thinking about how to move forward against cancer."

Alastair M Thompson
Professor of Surgical Oncology,
University of Dundee and Chairman,
NCRI Breast Clinical Studies Group

The Charity

ICPV was registered with the Charity Commission in October 2010, with the objects of "the promotion of good health among those suffering from cancer by participating in clinical research and the sharing of information with health professionals and patients."

Our trustees

Appointed on 18 October 2010

Margaret Wilcox	President
Adrienne Morgan	Chair
Jill Bartrop	Treasurer
Daphne Havercroft	Secretary
Carolyn Morris	

Appointed on 23 May 2011

Mairead MacKenzie
Hilary Blackburn

Do you shop on-line?

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If you do then raise money for free for ICPV everytime you shop online. There's no catch.
www.easyfundraising.org.uk/causes/icpv/

"I think it's really helpful for the academic community to have active contacts with a group like this which strives to be independent. I have really benefited from the involvement of members of this group when developing the question and design of our more pragmatic breast cancer trials. We need more of you to keep us on the right track."

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

www.independentcancerpatientsvoice.org.uk

Financial information

Our costs mainly comprise of the costs of hosting our study days, and the costs associated with attendance at other meetings. We have no paid staff, and volunteers donate their time. No trustees received remuneration.

In 2009/10, our funding has come from several sources, including pharmaceutical companies, and other donations. We are aware that we need to remain independent of pharmaceutical companies. However, it is in the interest of all cancer sufferers that effective drugs are developed, and we feel that donations from pharmaceutical companies are 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 in order for all members to feel able to participate. Some ICPV members donate some of their fees or honoraria to ICPV.

The surplus for the year was £5,889. This surplus has been transferred to unrestricted funds. The trustees believe that this is essential to enable the charity to continue to organise its activities without necessarily obtaining advance funding. The level of reserves will be kept under review.

Summary of accounts for the period ended 31 December 2010	
Income	**£**
Donations: pharmaceuticals	4,500
Donations: other	4,049
Bank interest	5
Total income	**8,554**

Expenditure	**£**
Study days	1,943
Other conferences and meetings	555
Other costs	167
Total expenditure	**2,665**
Surplus for the year	**5,889**

The surplus has been carried forward as unrestricted funds.

Speakers and organisers of meetings have donated their time. The estimated value of these donations in kind totalled £10,500.

The full set of accounts can be downloaded from the ICPV web site www.independentcancerpatientsvoice.org.uk

Independent Cancer Patients' Voice is a **patient advocate** group led by **patients for patients.** By **bringing** the **views** and **experience** of cancer patients, their family and carers, to the cancer research community, we aim to **improve outcomes** for **every** cancer **patient** in the delivery of **new treatments**

Independent Cancer Patients' Voice is a charity registered by the Charity Commission for England and Wales (no.1138456) registered office 17 Woodbridge Street, London, EC1R 0LL.

www.independentcancerpatientsvoice.org.uk

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