Clinical research:
Benefits from patient involvement:
The evidence

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independent cancer patients' voice

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Independent Cancer Patients' Voice is a patient advocate group led by patients for patients. We bring the views and experience of cancer patients, their families and carers, to the cancer research community. We believe that clinical research and practice will benefit more patients more quickly if people affected by cancer are partners with clinicians and healthcare professionals, rather than passive recipients of healthcare.

www.independentcancerpatientsvoice.org.uk

LORIS

The LOw RISk DCIS Trial

ICPV participation speeds up the process of turning a trial idea into a workable design, brings a welcome new perspective to the whole procedure and ensures the correct questions are asked
Adele Francis, University Hospital, Birmingham

ICPV have been **invaluable** to our translational research program eg TRACERx, trial concept development, protocol writing and regulatory submission. Their network and attention to detail is unparalleled and helps us adapt to the needs of patients, rapidly **accelerating** approval processes and **hastening** trial recruitment.
Charles Swanton UCLH

Great feedback from the group - and we are using it to **improve** our proposal PRESCRIBE
Iain MacPherson, Beatson West of Scotland Cancer Centre
Anna Campbell, Edinburgh Napier University.

MENOS 4

Funded by breast cancer now

ICPV have played a central role in setting the agenda for MENOS4 as well as helping to develop the study from inception to delivery. As a researcher a particular benefit of ICPV is that it is clear the **members understand research** and the role that service users can play in influencing the research agenda and direction. It is also of great benefit that they have a **structured organisation** that members can fall back on for mentorship and support.
Dr Deborah Fenlon , University of Southampton

ICPV provide an invaluable patient perspective, right from **the inception of a study** idea though the funding application process and onto the development of patient material and advice regarding **recruitment**. They ensure the patients views and voice are heard loud and clear
Carlo Palmieri, University of Liverpool

ICPV has made an **invaluable** contribution to YoDA BRCA, providing instrumental insight from a patient's perspective, contributing to research activities from editing patient facing documents to disseminating the research results.
Dr Chloe Grimmett, University of Southampton

RESTORE

Patient advocates from ICPV were very actively involved in supporting the design of the intervention as well as the design and delivery of the exploratory trial to test the feasibility and acceptability of the RESTORE resource in real life settings. They have both continued to champion RESTORE.
Claire Foster, University of Southampton

ICPV made a major contribution to the working group discussions for the POSH clinical trial. They reviewed the study material carefully and provided an **intelligent, rational, balanced** and extremely valuable perspective to help formulate the final plan to present to the ethics committee.
Diana Eccles

ICPV has been vital in improving the POSNOC trial design, ensuring outcomes important to patients are measured.
Amit Goyal Royal Derby Hospital

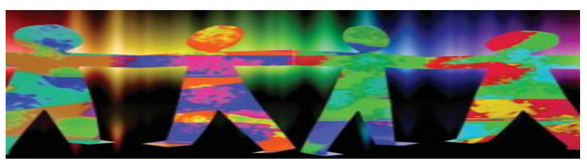
ICPV guided us through the potential "minefield" of patient **acceptability with serial biopsies**, blood tests and imaging for **NEO-RT**. ICPV will be a key member of the trial management group when the study opens.
Charlotte Coles

Mammo-50 optima

personalised treatment of breast cancer

ICPV has **influenced the design, information, consent, trial management and processes** for PERSEPHONE. Also for OPTIMA and MAMMO-50 where ICPV organised PPI focus groups to determine the experiences and views of the trial design, information and trial questions. 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' views throughout the trial process.
Janet Dunn Warwick Trials Unit

ICPV members have been involved with development and design of many trials at the Cambridge Breast Unit. Their feedback about **patient views on acceptability** of upfront BRCA testing in PARTNER (a neoadjuvant trial for high risk and hereditary breast cancer) **shaped the decisions** about the trial design. In another study dealing with whole genome sequencing their feedback regarding patient information leaflets led the ethics committee reviewing the project to comment on **how well written** the documentation was. They form an integral part of our team.
Jean Abraham



ICPV has been a key player in the establishment and activities of the Cancer and Nutrition NIHR infrastructure collaboration since its inception in 2014. They help us **ensure the patient voice is heard** at all levels of the collaboration's work, including recruitment of other ICPV members onto other work streams.

ICPV members have been crucial to developing heart-sparing radiotherapy for breast cancer patients in the HeartSpare Plus trial, particularly in trying out new techniques. **Clear and honest** feedback has helped us to make techniques more tolerable and comfortable for others.
Anna Kirby, Royal Marsden

The involvement of lay people in collections of tissue samples for research has been **critical** in allowing **professionals to feel confident** about what can reasonably be asked of patients. Without this input, i**t is highly unlikely that** our trials of presurgical treatments **could have been successful**.
Mitch Dowsett, Royal Marsden Hospital

PIONEER

My experience over the last few years has been that ICPV members provide excellent, thoughtful and rapid feedback on a range of research projects.
Dr. Richard Baird
Addenbrooke's Hospital

PRIMETIME

ICPV members have played **a fundamental** role in shaping the study design for PRIMETIME, so that it is acceptable to patients (and funders!) They have also led on **producing patient decision aids**, which will really help patients understand quite complex risk/benefit concepts.
Charlotte Coles

ICPV have been involved in the **conceptual and practical** development of the PEACE study from the outset. Their experience and input has been invaluable.
Charles Swanton UCLH

Persephone

The Persephone Trial is indebted to ICPV for their help and support to the trials team in Warwick and Cambridge and the women who participated for helping us **address recruitment issues** and **supporting us** through a challenging 8 year recruitment phase. We completed with over 4000 patients recruited to answer such an important question – Can the length of standard adjuvant trastuzumab be safely reduced? **Thank you**
Helena Earl Chief Investigator.