

Access and Consent in Biobanking Workshop Newcastle 10th October 2012

Response to the NCRI Template for Access
Christine Allmark

Independent Cancer Patients Voice

- Patient advocate group run and lead by patients
- **Aim** - to bring the patients' voice to the cancer research community
- Members involved in clinical research
 - eg BCC Tissue Bank, many clinical trials
- Study days inform members and consider clinical research
 - eg DCIS trial, liver cancer, living with cancer
- Active Google group

ICPV Study Days

- Leeds - June 2009
 - Pathology & Tissue Banking
- Barts & the London – November 2009
 - IBIS results & Screening Debate
- Cardiff – May 2010
 - Trial design, metastatic MDT, Genetics
- Westminster – March 2011
 - Including “Dragon’s Den” for new Clinical Trials
- CRUK – February 2012
 - Cutting-edge cancer treatments: expense & expectation?
- Sussex – September 2012
 - Two day autumn workshop psychosocial oncology

every patient is a

Very Important Person

This is a message to all patients undergoing tests and treatments for cancer from a group of patients who have completed treatment. We are active participants in research which will lead to improvements in the diagnosis and treatment of cancer. You could join with us to help make a difference.

For many people, 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 been given the choice to participate – even if this would only benefit others in the future.

You could be very influential in improving services and treatments for future patients. You could take part in clinical trials. Or, after your treatment, you could add your unique patient perspective to the design and conduct of clinical trials. If you changed your mind, you could withdraw at any stage and your standard of care would not change.

Breast cancer is an excellent example of quality clinical research leading to improved treatments and a big 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 for the individual patient.

But, there is so much more to be learned about all cancers. Many more patients need to be offered entry to clinical trials. And clinical research needs input from the patients’ unique perspective.

how can you become involved?

- 1) Ask your Nurse or Doctor about clinical trials or studies which may be appropriate for you.
- 2) Ask if you can donate some blood or tissue to be used in research.
- 3) Ask about opportunities for patients and carers to participate in improving cancer services and research.

independent cancer patients' voice

www.independentcancerpatientsvoice.org.uk

Independent Cancer Patients' Voice is a patient advocate group aware of the value of medical research to public health and the national economy. We believe that medical research in the UK needs a group, whose strategy is led by patients. We bring the opinions, views and experience of cancer patients, their family and carers, to the cancer research community.

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



www.ncri.org.uk
www.ncm.org.uk

what we are looking for in a member of ICPV

- An interest in finding out more about cancer and research.
- To help us make a difference in the research community, so that future patient benefit can be gained from working together.
- To provide an advocate patient/carer perspective as part of a team.
- An ability to give time to the group and its activities.
- A willingness to attend study days, meetings and to develop your understanding.
- To take part in the online discussion group
- To be a good listener and to contribute effectively in a variety of settings.
- Enthusiasm and a sense of humour would be welcomed.
- The need to be able to work within your own health limits.
- The ability to respect and observe confidentiality

what can we offer you as a member of ICPV

- To work with research professionals and peers to improve the patient experience.
- To be a member of an independent group who can provide direct patient experience as advocates to the research community.
- To work within the National Cancer Research Institute framework to ensure monitoring and governance.
- To support you as a group member.
- To work as a team.
- To give you opportunities to increase your knowledge and understanding of cancer research.
- Out of pocket expenses.

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But, there is so much more to be learned about all cancers. Many more patients need to be offered entry to clinical trials. And clinical research needs input from the patients' unique perspective.

how can you become involved?

- 1) Agree to donating your blood and/or tissue to the Breast Cancer Campaign Tissue Bank to be used in research.
- 2) Ask your Nurse or Doctor about clinical trials or studies which may be appropriate for you.
- 3) Ask about opportunities for patients and carers to participate in improving cancer services and research.

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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



researching the cure

TISSUE BANK

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

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We support the work of the Breast Cancer Campaign Tissue Bank

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 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.

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.

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.

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

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.

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NCRI Access Template

- Interesting document meriting attention
- Limits of use and availability of collection-
main principle should be for patient benefit
- Eligibility for access and prioritisation- for
patient benefit
- Application for access example of information
required-how tissue used for patient benefit

NCRI Access Template

- Emphasis on research for patient benefit
- Improve outcomes for patients
- Lay involvement at every stage of access approval including scientific assessment
- Breast Cancer Campaign Tissue Bank example
- Restore public trust in biobanking

Workshop on Access and Consent in Biobanking 2012

Thank you for the invitation

Thank you for listening

Any questions?

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