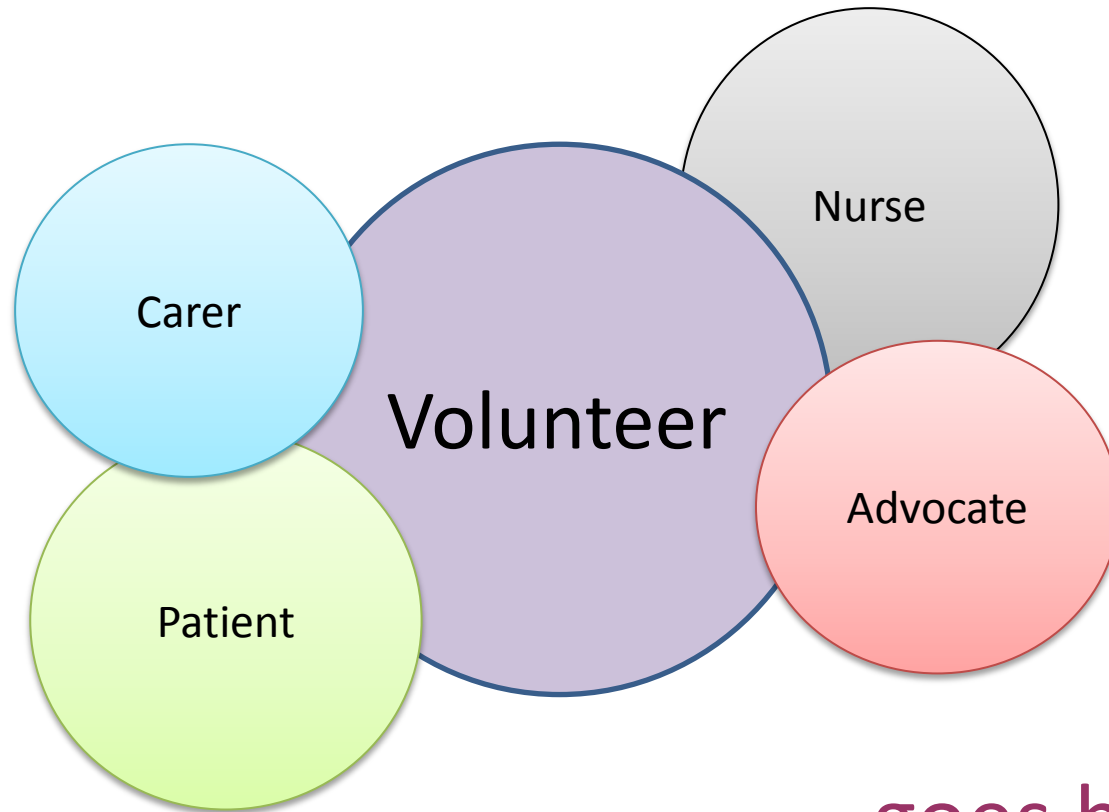




We believe that clinical research and practice is improved by patients being **partners** with clinicians and healthcare professionals, rather than passive recipients of healthcare

Donating Tissue – My Interest...



...goes back 40 years

Patient Advocate Influence

- Suggested groups collecting tissue should work together
 - led to the formation of a larger tissue bank.
- Won over the sceptical
- Ask the “elephant in the room” question
- Changes to Tissue Access policy
 - Patient benefit must be clear
 - Understandable lay summary before review
 - Discussion on application before decision
- Patient to Patient Leaflet



**breast
cancer
CAMPAIGN**

TISSUE BANK

researching the cure

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.

We support the work of the Breast Cancer Campaign Tissue Bank

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

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.

**independent
cancer patients' voice**

www.independentcancerpatientsvoice.org.uk

Patient View...

We feel that there is an important role for PPI in both educating professionals so that they feel more comfortable approaching potential donors and also in raising public awareness of the need for tissue donation

Current ICPV Activity

- The need for metastatic and post-mortem tissue
- Collaboration with researchers at UCL, Barts, Christie, GSST, RMH, Brainstrust
- Executive membership Confederation of Cancer Biobanks
- Membership HTA stakeholder and fees group

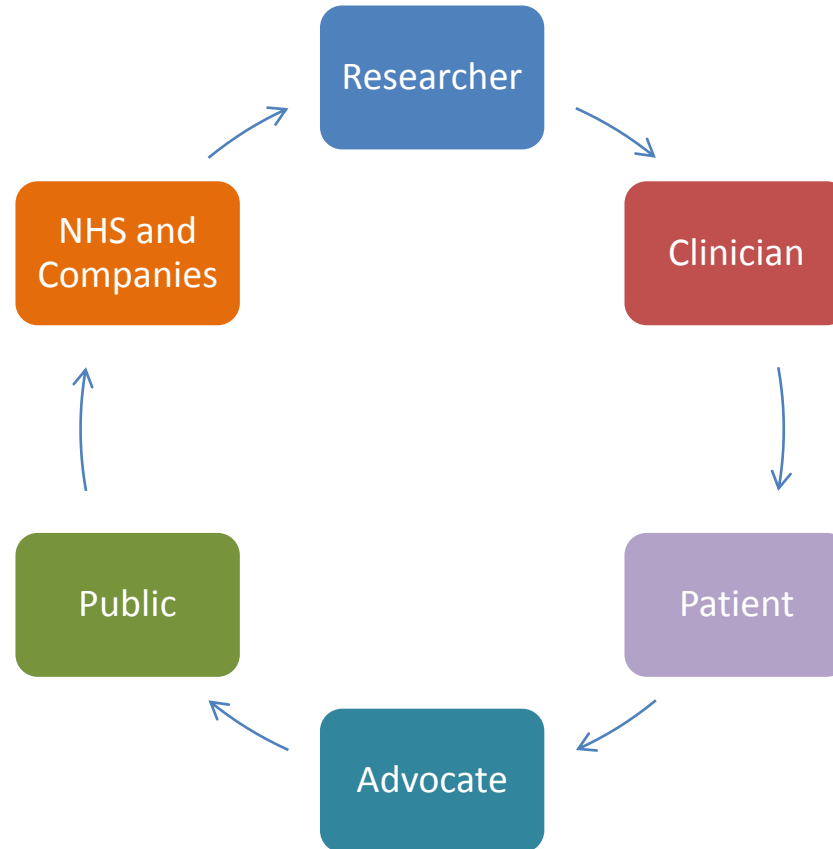
Conferences on Tissue Banking – 2013

- Mar – Reach to Recovery, Cape Town
- Sep – ECCO Conference, Amsterdam
- Oct – SWSH Cancer Research Network
- Nov – NCRI Conference, Liverpool
- Nov – CCB and RC Pathologists
- Dec – Britain Against Cancer Conference

Collaboration

- Important in metastatic tissue donation
- Prof. Swanton's team at UCL PEACE & TracerX
- Dr. Wilkins trainees at GSST
- Public guide to tissue donation

Communication



Current & Future

- Constructive PPI for researchers and biobanks (including GEL and UK Biobank)
- Expedite production of public guide
- Co-host public meeting
- Continue working on consent issues with help from Victoria Chico at Sheffield School of Law

Thank you for listening...
...any questions?

Suggestions also very welcome!