

### CCB Lay Members Maggie Wilcox and Derek Stewart provide their thoughts on the current situation in patient involvement in biobanking.



As previous cancer patients and people who have been involved in biobanking organisations for several years we are still surprised at the lack of genuine lay involvement in research tissue banks and large cohort studies in the UK. Patients and the public as tissue

donors are key stakeholders for any organisation or project that is collecting human samples for research. Without their support and trust there would be no samples and many organisations rely on the fact that many research participants give their consent without actually being aware of what research may be undertaken or whether the sample will ever actually be used. Involving them provides reassurance that research is for genuine patient benefit and ethical considerations and high quality standards are maintained.

Biobanks and large epidemiological studies risk losing public trust by not engaging and involving them. In this article we are featuring some of the CCB member biobanks who have involved patients to show the value that this can bring and also illustrate the benefits of embedding this activity throughout the organisation of the biobank; a position that the NCRI and Confederation of Biobanks are fully supportive of and recommend in their biobanking standard.

In the early days of planning both the Wales Cancer Bank (WCB) and Breast Cancer Campaign Tissue Bank (BCCTB) patients and lay persons were involved in discussions about the scope and proposal for developing the tissue banks.

In Wales patients were part of the Steering Group that developed the bid for funding and establishment of the tissue bank. They also provided key input into the participant information sheet and consent forms as well as advising on the Ethics committee application and when to approach patients regarding tissue donation.

The input on this latter aspect was vital. “We would have had much more complicated processes and caused ourselves issues if we hadn’t involved our Lay Liaison Group”, Alison Parry-Jones, manager of Wales Cancer Bank told us. “We had pre-conceived ideas of how sensitive patients might be at the time of being diagnosed with cancer and were told very firmly by our lay colleagues that we should just go ahead and approach them. If it’s not a good time they’ll tell us but they are people they’re not made of glass.”

This challenging of pre-conceptions was also apparent during the establishment of the BCCTB who included two patients on their Management Board when the applications to host the bank were being reviewed. Alastair Thompson, Chair of BCCTB highlights, “As researchers and clinicians we saw this as a competitive process but rather than looking for a single winner, our lay colleagues challenged us to rethink the process and said – ‘there are several good bids - why can’t they work together to create a virtual bank?’ It’s fair to say the altruism of patients donating tissues to the bank is enhanced by those patient advocates guiding the workings of the bank.”

This process was a learning opportunity for both the lay members and the professionals involved. We were able to increase our understanding of cancer biology and biobanking processes and our professional colleagues their understanding of the concerns and needs of potential donors.

Indeed for brainstrust the development of the bank wouldn’t have got off the ground without patient and lay support. ‘Lay involvement is putting the collection of brain tumour tissue on the map’, commented Helen Bulbeck, Director of brainstrust.





‘Talking about tissue donation means that patients are carving out the time and space to raise this issue with clinicians so that patients are driving the agenda.’ Archive brain tumour tissue is currently being recorded into one UK virtual brain tumour tissue bank, soon to be followed by post surgical collection and

recording of brain tumour tissue across several neuroscience centres. This project will provide the interface that is needed between researchers, patients and brain tumour tissue, giving easy access to the right tissue, in sufficiently large numbers and of high quality. It will support a diverse range of brain tumour research projects and change the face of neuro-oncology research. And it’s all down to the patient.

At BCCTB there are lay members on the Access Committee and all researchers applying for samples need to complete a lay summary of the research they plan to undertake with the samples.

In Wales lay members are part of a Lay Liaison and Ethics Group and provide input and advice on wider aspects of the tissue bank such as their communication strategy. ‘We feel we’re the

ambassadors of the bank”, said Bob Hall, the Group’s Chair, “We provide a vital connection between the bank and the potential donors. We’ve lobbied government and encouraged the bank to go out into the community to give talks to patient groups.”

The role of ambassador and advocate is one that many patients take on when they become involved in research and tissue banking is no different. Raising of awareness of research using tissue samples is becoming even more important with the development of genomic technologies and the need for samples to be collected at multiple timepoints to monitor the progression of diseases like cancer. The consent and willingness of patients and the public to participate in this research will be vital and the involvement of patients and the public will help ensure that the trust and transparency required can be maintained.

From the patients perspective this can be a very rewarding activity. It is fascinating and exciting to learn about the science being carried out with the samples and donors really want to know how they are helping progress in medical research. Many biobanks don’t even send a newsletter to their donors or have information on their website about the research being carried out. How will they continue to be sustainable if they don’t capitalise on the additional resource that their donors can provide in becoming advocates for them?