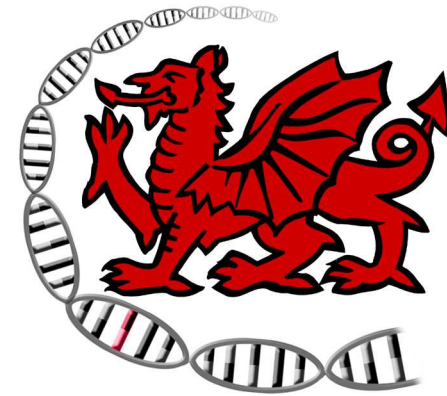


THE WALES CANCER BANK – PATIENT ENGAGEMENT

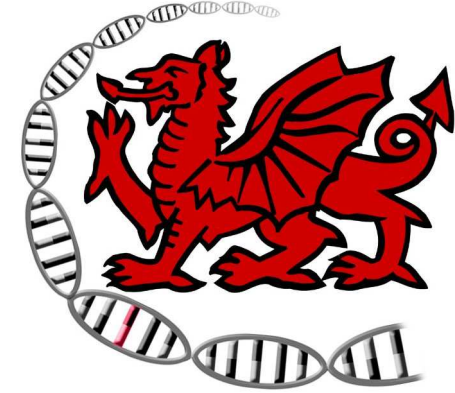


WALES CANCER BANK
BANC CANCER CYCORU

Dr Alison Parry-Jones

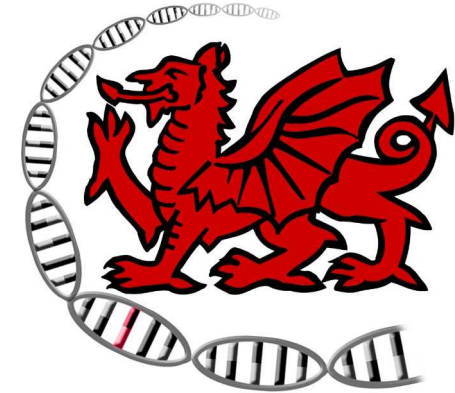
Wales Cancer Bank (WCB)

Aim

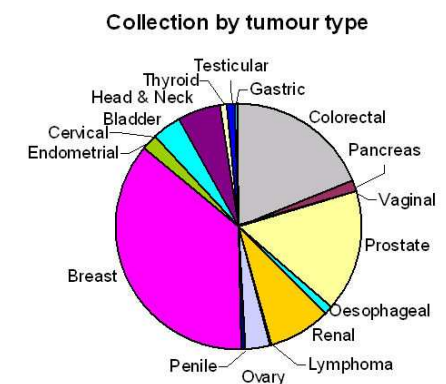
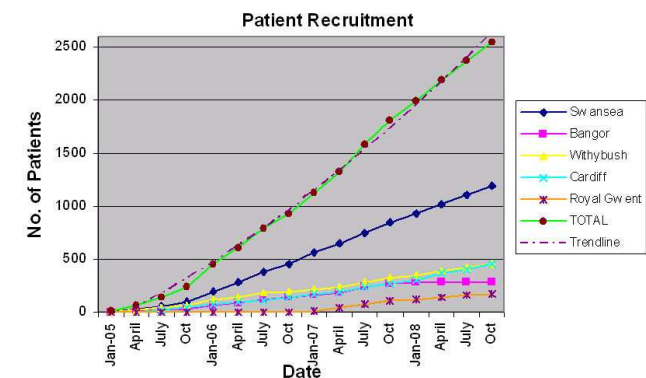


- To provide a population based collection of tissue and blood samples from all patients in Wales undergoing an operation where cancer is a possible diagnosis
- In the hope that, eventually, the provision of a standardised, quality assured collection of tissue samples, linked to clinical outcome, will help identify novel profiles for prediction and prognosis which will lead to individualised treatment, thereby avoiding unnecessary or ineffective treatments for patients

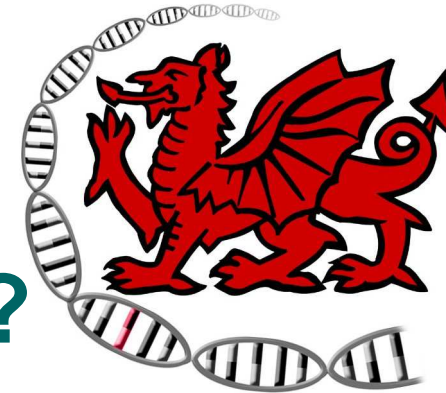
R² (recruitment and regulation)



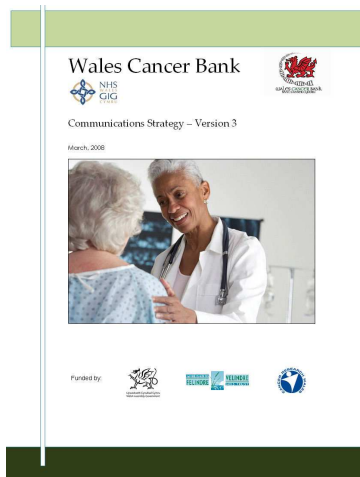
- Started consenting patients in February 2005
- 2530 patients so far, from 7 hospitals
- 17 different tumour types, variety of sample types
- Licensed by the Human Tissue Authority
- Approval Wales MREC



How are patients involved?

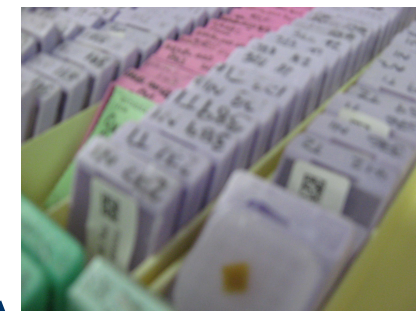


Patient Involvement



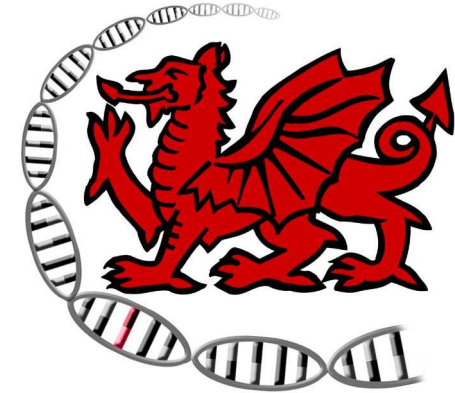
Patients as advisers

Patients as advocates

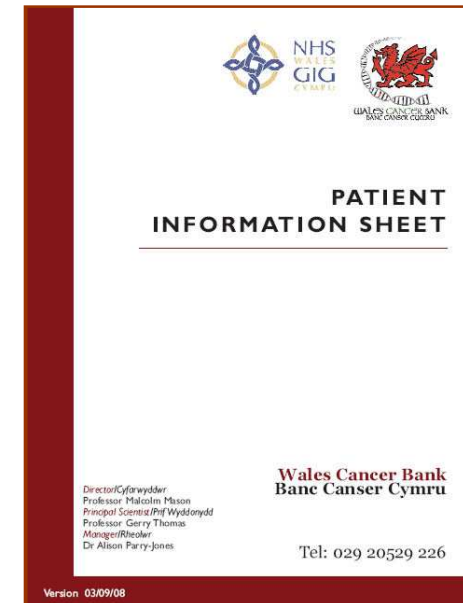


Patients as donors

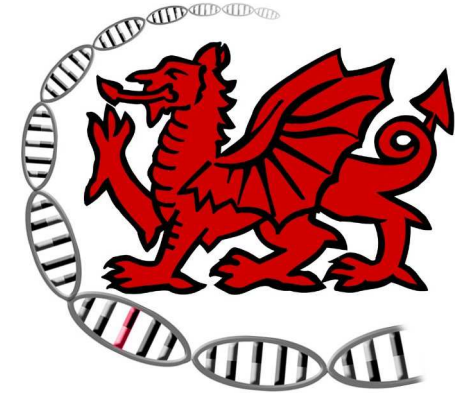
Patients as Advisers



- Patient input on original Steering Committee set up in 2002
- Patient Liaison group formed in 2003
 - Patient information sheets
 - Easy to understand, NO acronyms
 - Consent forms
 - MREC submission
 - Protocols and pathways

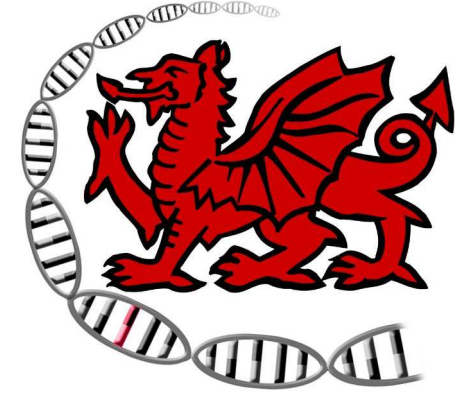


Patients as Advisers 2



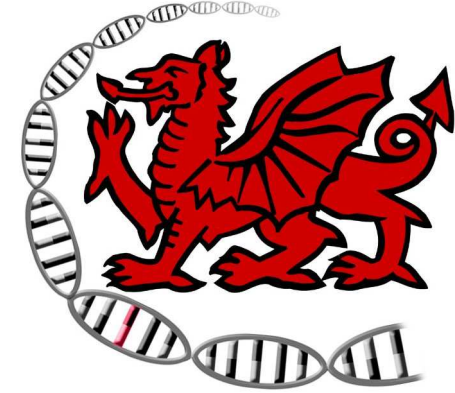
- Reformatted into Lay Liaison & Ethics group on 2007
 - Communication Strategy
 - Informing public, patient groups, policy makers, healthcare professionals and funding bodies
 - Review patient documentation
- Patient representative on Advisory Board and Executive group

Patients as Advocates



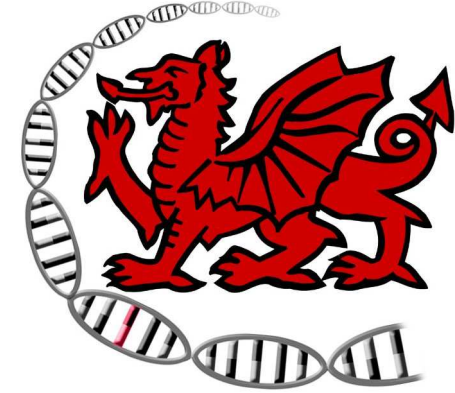
- Public launch in Cardiff in 2004
 - 42% attendees patients/patient representatives
- Patients giving press interviews
 - Support and training
- Lobbying politicians
- Patient forum and newspaper articles
- Attending conferences

Patients as Donors



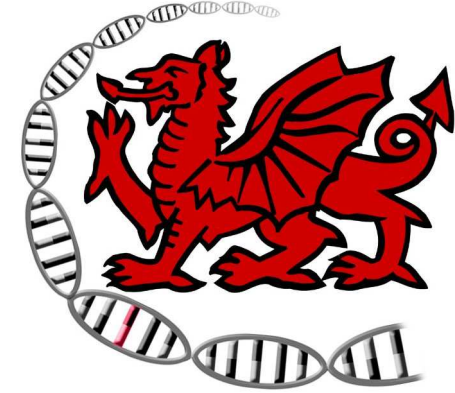
- 98.2% patients agree to consent when approached pre-surgery
- 99.5% patients agree retrospectively
- 57% of WCB donors are female, 43% male
 - Breast largest collection
- 68% are over 60
- Men more reluctant to act as control

Patients as Donors 2



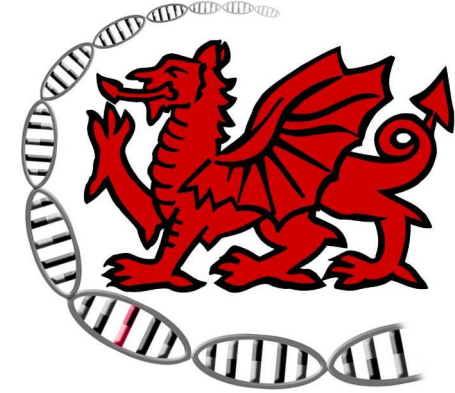
- No common reason for not consenting
- Pharmaceutical company involvement not an issue
- Gathering refusal reasons:
 - ‘I’ve got cancer and I don’t want to help anyone else’
 - ‘The arm of the chair is sticky’
 - ‘I don’t want my wife cloned!’

What have we learnt?



- Patients are at the heart of biobanking
- They want to get involved and feel it is their decision not the doctors
- Patients are very strong advocates
- Patient groups are good information forums
- Patients bring a 'human' perspective to project design and want to get involved in research projects

Contact details



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